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Exploring transition to adulthood from the  
perspectives of young people with high  
functioning autism and their families: A  
research portfolio

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Doctorate in Clinical Psychology



THE UNIVERSITY  
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May 2015

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## Table of Contents

<b>D. Clin. Psychol. Declaration of own work .....</b>	<b>2</b>
<b>Acknowledgements .....</b>	<b>3</b>
<b>Thesis abstract.....</b>	<b>5</b>
<b>Chapter 1: Prevalence of depression in children and young people with high functioning autism spectrum disorders: a systematic review .....</b>	<b>7</b>
Abstract.....	7
Introduction.....	8
Methods.....	11
Results .....	14
Discussion .....	24
References.....	35
<b>Chapter 2: Exploring transition to adulthood from the perspectives of young people with high functioning autism and their families.....</b>	<b>47</b>
Abstract.....	47
Introduction.....	48
Methods.....	52
Results .....	60
Discussion .....	82
References.....	91
<b>Full reference list for thesis .....</b>	<b>95</b>
<b>Appendix 1: Relevant Autism manuscript guidelines .....</b>	<b>108</b>
<b>Appendix 2: Quality criteria .....</b>	<b>111</b>
<b>Appendix 3: Coding of quality according to criteria detailed in Appendix 2.....</b>	<b>114</b>
<b>Appendix 4: Relevant instructions for authors for the Journal of Autism and Developmental Disorders .....</b>	<b>118</b>
<b>Appendix 5: Ethics approval from the NHS National Research Ethics Committee, North of Scotland .....</b>	<b>122</b>
<b>Appendix 6: Participant information sheet for young people.....</b>	<b>124</b>
<b>Appendix 7: Participant information sheet for parents .....</b>	<b>126</b>
<b>Appendix 8: Consent form for young people.....</b>	<b>128</b>
<b>Appendix 9: Consent form for parents .....</b>	<b>130</b>
<b>Appendix 10: Interview topic guide .....</b>	<b>132</b>
<b>Appendix 11: Extracts from reflective log.....</b>	<b>133</b>
<b>Thesis word count: 21743</b>	

## **Thesis abstract**

**Introduction:** Young people with high functioning autism spectrum disorders (HFASD) are particularly vulnerable to developing comorbid depression. It has been suggested that young people with HFASD and comorbid mental health difficulties are likely to experience difficulties during the transition to adulthood. This transition involves significant changes in both services and daily routine, something which people with HFASD often find difficult.

**Aims:** This thesis includes two distinct pieces of work. A systematic review aiming to understand the prevalence of depression in children and young people with HFASD. A qualitative study aiming to explore transition to adulthood from the perspectives of young people with HFASD, who currently attend child and adolescent mental health services (CAMHS), and their families.

**Methods:** For the systematic review, literature reporting the prevalence of depression in children and young people with HFASD was systematically searched and reviewed. For the qualitative study, data collection and analysis followed the principles of Interpretative Phenomenological Analysis (IPA). Four dyads of a young person with HFASD and a parent were interviewed.

**Results:** The systematic review identified 18 studies which described results from 17 independent samples. The prevalence reported varied from 0% to 83%. This variation is most likely explained by methodological differences between studies. In

the qualitative study, transition to adulthood was described as a process during which the young person is developing independence, while parents continue to have a role in providing support. Current and future support needs were perceived differently by the young people with HFASD than their parents, with the young people reporting less need for support.

**Conclusions:** Further research is needed to better understand how to assess depression in this population, as well as the impact of age, gender, setting, medication use and other comorbidities. Transition is a time of uncertainty and change for young people, during which they become more independent of their families. Services need to consider the impact of these processes and young people's perceptions about what it means to receive support.

# **Chapter 1: Prevalence of depression in children and young people with high functioning autism spectrum disorders: a systematic review**

**Key Words:** Depression, HFASD, children with autism, MDD

## **Abstract**

Children with high functioning autism spectrum disorders (HFASD) are vulnerable to developing comorbid depression. However, depression is difficult to assess in this population. This study systematically searched and reviewed the literature reporting the prevalence of depression in children and young people with HFASD. The prevalence reported in the identified literature varied from 0% to 83%. This variation is most likely explained by methodological differences between studies. Further research is needed to develop standardised methods of assessing depression in children with ASD. Research is also needed to gain a better understanding of the impact of age, gender, setting, medication use and other comorbidities on the prevalence of depression in children with HFASD.



## **Introduction**

A large proportion of children and young people with autism spectrum disorders (ASD) also experience comorbid psychiatric disorders including depression, anxiety, attention deficit hyperactivity disorder (ADHD) and disruptive behaviour disorders (Mazzone et al., 2012). One explanation for this is that the core difficulties associated with ASD, including difficulties with understanding emotions, understanding social situations, particularly what other people are thinking (theory of mind (Baron-Cohen, 2000)) and a need for routine and predictability may make people with ASD vulnerable to developing mental health difficulties (Hebron and Humphrey, 2014).

It has been proposed that children with ASD who do not have an associated learning disability (LD) (including Asperger Syndrome (AS) and High Functioning Autism (HFA), referred to collectively as High Functioning ASD (HFASD)) may be at particular risk for developing mental health difficulties (Lopata et al., 2010). These children are more likely to have insight into their difficulties and be aware of the differences between them and their peers, which may have negative effects on their self-perception (Magnuson and Constantino, 2011). Furthermore, these young people are more likely to be educated in mainstream settings, which have higher social demands and greater potential for negative peer interactions (Nebel-Schwalm and Worley, 2014). Comorbid depression can result in greater levels of withdrawal, aggression and family distress, as well as increasing the risk of suicide (Matson and Nebel-Schwalm, 2007; Hannon and Taylor, 2013). Understanding which comorbidities are more prevalent in ASD, and factors associated with increased

prevalence may allow for the development of programmes aimed at prevention and early intervention (Steensel et al., 2013).

### *Assessing depression in children with ASD*

Reported prevalence rates have varied across all comorbid disorders (Mazzone et al., 2012). However, the prevalence of depression is an area of research where findings have been particularly variable (Gjevik et al., 2011). This has been linked to the difficulty in identifying depression in children with ASD (Magnuson and Constantino, 2011). Children with HFASD have difficulties with social communication alongside cognitive difficulties in theory of mind, executive functioning and processing complex information (Leyfer et al., 2006). These impairments create difficulties in self-reflection and reporting of emotions, making it difficult to assess depression based on self-report alone (Leyfer et al., 2006; Magnuson and Constantino, 2011). Furthermore, there is an overlap between the behavioural symptoms of ASD and those of depression, such as poor eye contact, a monotonous tone of voice and difficulties with sleep and appetite, which restrict assessment of depression based on observation or the report of a carer (Nebel-Schwalm and Worley, 2014; Henry et al., 2014). This also means that symptoms of ASD may hide symptoms of depression, making recognition more difficult (Magnuson and Constantino, 2011). Despite these difficulties, Lecavalier and colleagues (2009; 2011) demonstrated, using confirmatory factor analysis, that the DSM-IV diagnostic criteria for psychiatric disorders are valid in children with ASD. However, it is still a matter of debate as to whether depression presents in ASD in the same way as the typically developing population (Witwer et al., 2012).

### *Previous reviews*

Stewart et al. (2006) comprehensively reviewed the literature around depression in autism, describing both the prevalence and presentation of depression. This review, which included both children and adults, concluded that depression appeared to be common in people with ASD. However, Stewart and colleagues' literature search is now over 10 years old, and their conclusions were based largely on case studies or the combined results of studies which included children and studies involving only adults. Furthermore, due to the lack of available literature at the time, Stewart and colleagues did not differentiate between depression in HFASD and in those with ASD who also have an LD. More recently, Magnuson and Constantino (2011) reviewed the literature on depression in children with ASD. They reported highly variable rates of depression, concluding that this variability was due to difficulties assessing depression in children with autism, and the lack of a 'gold standard' assessment tool. However, their search strategy used limited search terms in one database. Furthermore, their results included only a short section on prevalence, which did not provide a comprehensive analysis of factors which may have led to the variable results they report. Several reviews (Skokauskas and Gallagher, 2010; Mazzone et al., 2012; Mannion and Leader, 2013) have considered the comorbidity of all psychiatric disorders with ASD. However, the broad nature of these reviews means they are unable to explore factors affecting any one disorder in detail. Furthermore, Mazzone et al. (2012) only included articles meeting a certain score on a quality assessment, which only seven articles on depression met. Matson and Cervantes (2014) reported that between 2008 and 2013 more than seven papers a

year were published on comorbidities in ASD. Therefore, it is likely that the literature available has increased significantly, even since the most recent review.

### *Aim*

This systematic review aimed to understand the prevalence of depression in children and young people with HFASD. It was hypothesised that prevalence would be variable, therefore a secondary aim was to explore what factors contribute to this variability.

## **Methods**

### *Search strategy*

Databases were searched on 05/11/14 and 06/11/14. Using the OVID platform, Medline, Embase, ERIC and HMIC were all searched concurrently; CINAHL, PsycINFO, Psychology and Behavioural Sciences Collection were searched using the EBSCO platform and Social Services Abstracts and ASSIA were searched using the ProQuest platform. All databases were searched without date restrictions using the terms Autis\*, Asperger, Pervasive Development Disorder, PDD, ASD, HFASD in combination with the terms depress\*, MDD, comorbidity, psychiatric disorder, psychological disorder, bipolar, unipolar. Additionally, each database was searched separately using the thesaurus function to identify the broadest search terms for ASD and depression, which were used in combination with the 'explode' function. The reference lists of articles identified as relevant were searched and Web of Science, Pubmed and Scopus were used to identify articles which reference those which met the inclusion criteria.

### *Study selection*

After duplicates had been removed the relevance of all articles was established by review of titles and then review of the abstracts against the inclusion and exclusion criteria. Any articles which were not in English, did not report original research or reported case studies were removed at this stage. Full articles were then reviewed to establish if they met the following inclusion and exclusion criteria:

### *Inclusion criteria*

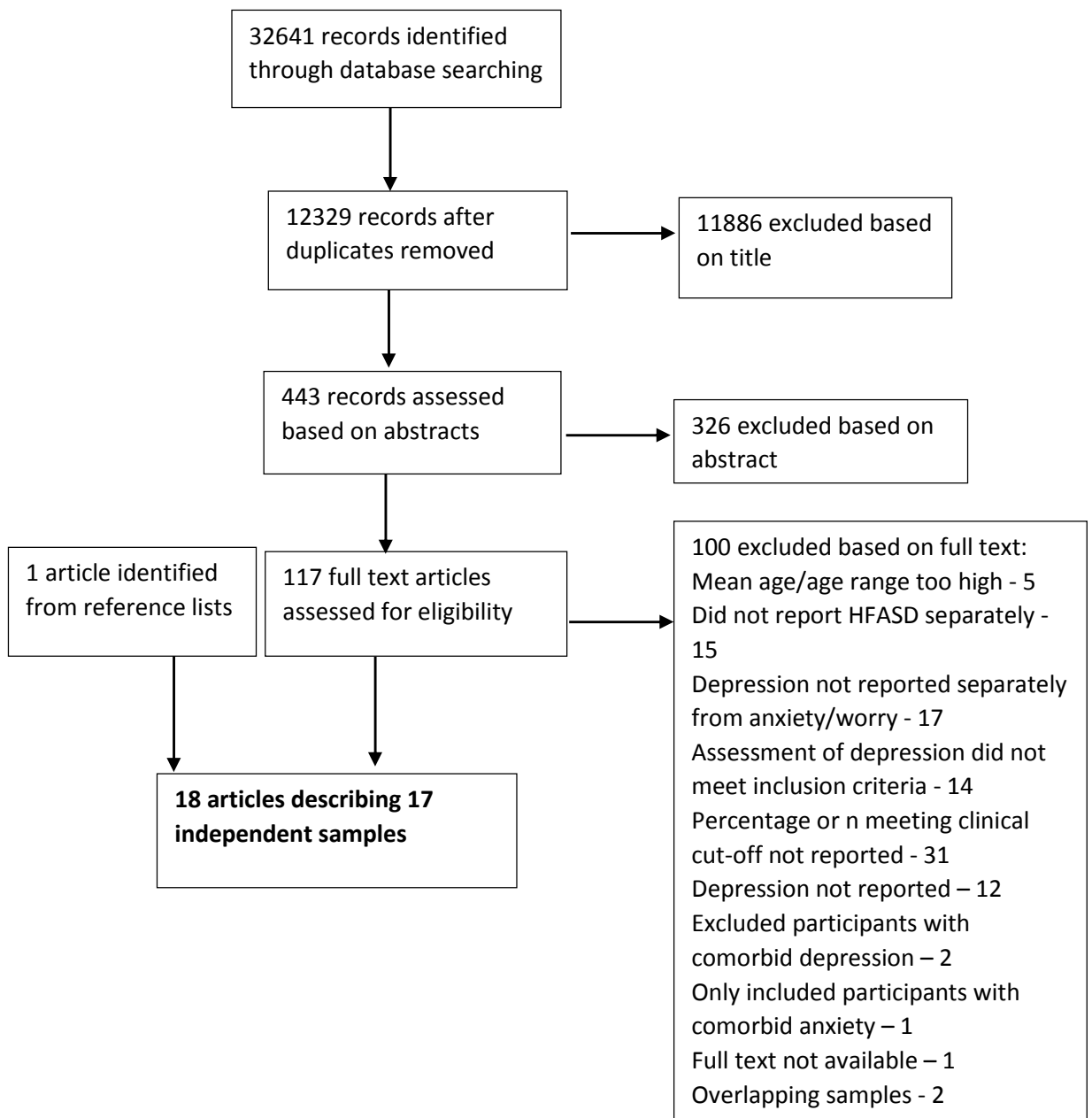
- Reports the prevalence of depression in children diagnosed with HFASD (defined as any ASD where the young person does not have a LD (studies were included if the lowest full scale intelligence quotient (FSIQ) reported was 65 or over if the average FSIQ was 70 or above)).
- Sample has a mean age under 18 and a maximum age of 24 or under.
- Depression had been assessed using a standard measure (either a (semi)structured interview or questionnaire) and the number or percentage reaching a clinically relevant cut-off is reported.
- Prevalence of depression is reported separately from other mental health difficulties.

### *Exclusion criteria*

- Criminal justice samples.
- Samples which only include children with ASD and a comorbid mental health diagnosis (i.e. anxiety).
- Samples which excluded children already diagnosed with depression.

20 articles were identified which met these criteria. Where multiple articles reported results from overlapping samples the most relevant article was included, or if both articles reported results from identical samples the articles were used jointly. 18 articles which described 17 independent samples were included (Figure 1).

Figure 1: Flow chart of literature search and article selection based on the recommendations in the PRISMA reporting guidelines (Moher et al., 2009).



### *Assessment of quality*

Quality criteria were developed based on the STROBE reporting criteria (von Elm et al., 2007) and the quality criteria developed for the assessment of prevalence studies by Shamliyan et al. (2011) to identify additional criteria relevant to sampling.

Additional criteria were also identified based on the literature, which appraised how ASD and depression were assessed and whether possible confounders such as other comorbidities and the use of psychoactive medication were considered. Each criterion was rated as either well covered (2 points), adequately addressed (1 point), poorly addressed (0) or not reported (0) following the criteria in the SIGN 50 guideline (Scottish Intercollegiate Guideline Network, 2011) (for full criteria see Appendix 2). This allowed a summary score out of 24 to be calculated. However, caution is recommended in the interpretation of summary scores as they reflect many diverse aspects of quality (Centre for reviews and dissemination, 2009). Eight papers, 47%, were independently rated by a colleague. Inter-rater agreement was high (Cohen's Kappa = 0.89, 93% agreement) and any differences were discussed.

### **Results**

The 17 studies identified reported the prevalence of depression across a total of 900 children and young people with HFASD. The prevalence of depression in these studies varied from 0% (Giovinazzo et al., 2013) to 83.3% (Mazzone et al., 2013). The studies varied in terms of how ASD and depression were assessed and the characteristics of the sample they included. Key results are reported in Table 1.

Table 1: Key results from the studies meeting the inclusion and exclusion criteria.

Reference	Country	N	% male	Mean age (range)	Setting sample recruited from	ASD assessment tools	Depression assessment tools	Informant	% depression	Related results	Quality Score (out of 24)
Giovinazzo et al. (2013)	Italy	86 <sup>a</sup>	89 <sup>a</sup>	11.9 (SD 7.1) <sup>a</sup>	clinical - psychiatry and neurology unit	ADOS, ADI-R	K-SADS and CDI	child (CDI)	0%		11
Green et al. (2000)	UK	20	100	13.75 (11-19)	clinical	ADOS, ADI	modified Isle of Wight Interview	parent	5% - MDD	25% dysthymia	15
Gurkan et al. (2008)	Turkey	40	90	10.8 (6-18)	clinical - autism clinic	ASSQ, ASDIF	K-SADS-PL	child, parent	10%		16
Hebron and Humphrey (2014)	UK	19	86 <sup>a</sup>	14.2 (11-17) <sup>a</sup>	education	prior diagnoses	BYI -II	young person	36.4%		13
Joshi et al. (2014); Joshi et al. (2010)	USA	217	87	9.7 (3-17)	clinical - general psychiatry	clinical interview only	K-SADS-E	parent	56% (lifetime), 39% (current) MDD		17
Kim et al. (2000)	Canada	59	90 <sup>a</sup>	12 (9-14)	clinical - ASD centres	ADI	Revised Ontario	parent	16.90%		16



							child Health Study				
Lopata et al. (2010)	USA	40	90	9.8 (7-13)	mixed	ADI-R	BASC-2	parent	40%		14
Mattila et al. (2010)	Finland	50	76	12.7 (9-16)	community and clinical (general hospital)	ASSQ, ADI-R and ADOS	K-SADS-PL	parent, child	14% (life time) 6% (current)		19
Mazefsky et al. (2011b) <sup>b</sup>	USA	38	82	12 (10-17)	clinical - ASD clinic	ADOS, ADI-R	ACI-PL, CDI-S	parent (ACI), child (CDI)	ACI - 15.8% MDD, 2.6% depression NOS CDI - 0%	28.9% sub-threshold (ACI)	17
Mazzone et al. (2013)	Italy	30	100	11 (7-16)	clinical - neuropsychiatry unit	ADOS	CDRS-R, CDI	child	CDI - 26.6%, CDRS-R - 83.3%		10
Mukaddes et al. (2010)	Turkey	60	100	11 (6 - 15)	clinical - autism clinic	clinical interview only	K-SADS-PL	parent, child	21.7% MDD, 6.7% depression NOS	1.7%, dysthymia	13
Mukaddes and Fateh (2010)	Turkey	37	87	10.9 (6-20)	clinical - private psychiatry	clinical interview only	K-SADS-PL	parent, child	29% MDD		14

Strang et al. (2012)	USA	95	86	11.7 (6-18)	clinical - autism clinic	ADOS or ADI-R/ ADI	CBCL	parent	30%	44.2% borderline	15
Vickerstaff et al. (2007)	Australia	21	86 <sup>a</sup>	11.9 (7-13) <sup>a</sup>	mixed – self and clinically referred	DISCO	CDI	child	29%	24% mildly depressed	16
Whitehouse et al. (2009)	Australia	35	80	14.2 (12-17)	education	CAST	CES-DC	young person	65.7%		9
Wilson et al. (2014)	USA	31	84	5.6 (3-6)	mixed	ABC	BASC-2	teacher	3.2%	22.6% at risk	13
Witwer and Lecavalier (2010)	USA	22	82 <sup>a</sup>	11.2 (6-17) <sup>a</sup>	mixed (mostly clinical)	ADI-R	P-ChIPS	parent	22.7% MDD	13.6% dysthymia	15

<sup>a</sup> Number/result for entire sample including some participants who did not meet inclusion criteria, <sup>b</sup> sample overlaps Mazefsky et al. (2010), Mazefsky et al. (2012).

ABC: Autism Behaviour Checklist, ADI(-R): Autism Diagnostic Interview (-Revised), ACI-PL: Autism Comorbidity Interview-Present and Lifetime Version, ADOS: Autism Diagnostic Observation Schedule, ASDIF: Autism Spectrum Diagnostic Interview Form, ASSQ: Autism Spectrum Screening Questionnaire, BSAC-2: Behavioural Assessment System for Children 2, BYI-II: Beck Youth Inventory – II, CAST: Childhood Asperger Syndrome Test, CBCL: Childhood Behaviour Checklist, CDI(-S): Childhood Depression Inventory (-Short form), CDRS-R: Children's Depression Rating Scale-Revised, CES-DC: Centre for Epidemiological Studies Depression Scale – Children's Version, DISCO: Diagnostic Interview for Social and Communication Disorders, K-SADS: Kiddie Schedule for Affective Disorders and Schizophrenia, MDD: Major Depressive Disorder, P-ChIPS: Children's Interview for Psychiatric Symptoms – Parent Version.

Thirteen of the studies had a primary aim to assess the prevalence of comorbidities in ASD. Three studies aimed to understand the impact of factors such as loneliness and friendship (Whitehouse et al., 2009), social competence (Vickerstaff et al., 2007) and demographic variables (Strang et al., 2012) on depression symptoms and one study aimed to explore the psychometric properties of self-report measures (Mazefsky et al., 2011b).

### *Assessment of ASD*

Six studies used two or more standardised assessment tools to assess ASD, seven used one standardised assessment tool, three studies relied on a non-standardised clinical interview alone and one study on prior clinical diagnosis. Ten studies included a standardised interview-based assessment tool as part of their assessment of ASD; six used the Autism Diagnostic and Observation Schedule (ADOS (Lord et al., 2000)), eight the Autism Diagnostic Interview (-revised) (ADI (-R) (Lord et al., 1994)), one the Diagnostic Interview for Social and Communication Disorders (DISCO (Wing et al., 2002)) and one the Autism Spectrum Diagnostic Interview Form (ASDIF – Turkish, English reference unavailable). Four studies included screening questionnaires for identifying risk of ASD; two studies used the Autism Spectrum Screening Questionnaire (ASSQ (Ehlers et al., 1999)), one the Childhood Asperger Syndrome Test (CAST (Scott et al., 2002)), one the Autism Behavioural Checklist (ABC (Krug et al., 1980)). Nine studies made diagnoses based on the DSM-IV or DSM-IV-TR diagnostic criteria, one the DSM-III-R criteria and two the ICD-10 criteria. The specific diagnoses reported by the studies varied depending on

the diagnostic criteria used and included HFA, AS, pervasive developmental disorder not otherwise specified (PDD-NOS), atypical autism, autism and ASD.

### *Assessment of depression*

*Measures used:* nine studies assessed depression using a semi-structured clinical interview. The most commonly used semi-structured interview was the Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS (Ambrosini, 2000)), which was used by six studies. One study used a version of the K-SADS which had been specifically adapted for children with ASD, the Autism Comorbidity Interview (ACI (Leyfer et al., 2006)). One further study each used the Children's Interview for Psychiatric Symptoms – Parent Version (P-ChIPS (Weller et al., 2000)) and the modified Isle of Wight Semi-Structured Informant and Child Interviews (Institute of Psychiatry). Apart from three studies using the Childhood Depression Inventory (CDI (Saylor et al., 1984)), all of the questionnaire or rating scale based studies used different self, parent or teacher report measures which were: the Beck Youth Inventory-II (BYI-II (Beck et al., 2006)), the Childhood Behaviour Checklist (CBCL (Nakamura et al., 2009)), Children's Depression Rating Scale-Revised (CDRS-R (Poznanski and Mokros, 1996)), Centre for Epidemiological Studies Depression Scale – Children's Version (CES-DC (Fendrich et al., 1990)), Behavioural Assessment System for Children – second edition (BASC-2 (Reynolds and Kamphaus, 2004)) and the revised Ontario Child Health Study (OCHS), which is a revision of the CBCL.

Overall, the reported prevalence of depression was lower in studies which assessed depression using a semi-structured interview (range 0% (Giovinazzo et al.,

2013) to 39% (Joshi et al., 2014)) compared to those which used a questionnaire or rating scale based methodology (range 0% (Mazefsky et al., 2011b) to 83.3% (Mazzone et al., 2013)). However, even in the six studies using the K-SADS, results varied from 0% (Giovinazzo et al., 2013) to 39% (Joshi et al., 2014). The highest prevalence (83.3%) was found by Mazzone et al. (2013) using the CDRS-R. However, in the same sample, Mazzone et al. (2013) reported a prevalence of 26.6% using the CDI. Mazefsky et al. (2011b) used both the ACI and the CDI-S and reported differing prevalence's of 18.4% using the ACI and 0% using the CDI. Giovinazzo et al. (2013) used both the K-SADS and the CDI and reported finding no incident of depression. However, they do not report results separately for the measures, or explain how the measures were combined, making this finding difficult to interpret.

*Informant:* six studies based the assessment of depression on parental report only; five on the child's report only; one on the report of teachers; four on the combined reports of parents and children, and one used different informants for different measures of depression. The greatest variability was in the self-report of the children and young people, where prevalence of depression varied from 0% (Giovinazzo et al., 2013) to 83.3% (Mazzone et al., 2013). This likely reflects the fact that, with the exception of Giovinazzo et al. (2013) (who also used the K-SADS but do not report who was involved in the interview), studies which only used children as informants also used questionnaires or rating scales to measure depression. In contrast, studies which included both the child and a parent as an informant all used the K-SADS and showed the most consistent results, with rates of current depression varying from 6%

(Mattila et al., 2010) to 29% (Mukaddes et al., 2010). However, for these studies, it is not clear what proportion of the interviews with parents and children were conducted separately and whether for all cases both a child and parent were interviewed. Furthermore, with the exception of Mattila et al. (2010), the studies do not report how the results from different informants were combined to make the decision on depression status.

#### *Characteristics of the samples*

*Age:* the studies reported on children with ages ranging from three to 20. With the exception of Wilson et al. (2014), all samples had a similar mean age of between 9.7 years and 14.2 years. Lopata et al. (2010), Mazzone et al. (2013) and Strang et al. (2012) all examined the association between age and symptoms of depression and found no significant effects. Strang et al. (2012) further reported that there was not a statistically significant difference in the mean age of those who met the criteria for depression and those who did not. In contrast, Wilson et al. (2014) reported that higher levels of depressive symptoms were associated with being older.

*Setting:* 10 out of the 17 samples were recruited from clinical settings, of which five were specialist autism clinics and the remainder in general psychiatry, neuropsychiatry or neurology. Two of the samples were recruited only through educational settings and five samples were recruited from a mixture of settings. Prevalence was most consistent in the samples recruited from ASD-specific clinics (range: 10% (Gurkan et al., 2008) – 30% (Strang et al., 2012)). The results varied

between those studies conducted in the same country, as well as between studies conducted in different countries.

*Other comorbidities:* 15 studies reported on comorbidities other than depression. The most common of these were ADHD (11 studies) and anxiety (15 studies). Rates of ADHD varied from 5% (Green et al., 2000) to 95% (Witwer and Lecavalier, 2010). With the exception of Giovinazzo et al. (2013), those studies reporting higher rates of ADHD tended to also report higher rates of depression. Joshi et al. (2014) reported that 83% of their sample had a lifetime diagnosis of ADHD and that 56% had a lifetime diagnosis of MDD. Witwer and Lecavalier (2010) reported a prevalence of ADHD of 95% and MDD of 22.7%. Mukaddes et al. (2010) reported a prevalence of ADHD of 65% and MDD of 21.7%. Green et al. (2000) reported a low prevalence of 5% for both major depression and ADHD and Wilson et al. (2014) reported a prevalence of depression of 3.2% and a relatively low prevalence of ADHD at 29%; although it should be noted that Gurkan et al. (2008) reported a high ADHD prevalence of 52.5% and a relatively low prevalence of depression (10%). Some studies reported specific anxiety disorders and others broader criteria of combined anxiety. Reported rates varied from 2.5% for generalized anxiety disorder (Gurkan et al., 2008) to 78% for 'anxiety disorders' (Mukaddes et al., 2010). The variation in what was reported as anxiety made it difficult to establish if there was a relationship between the prevalence of anxiety and the prevalence of depression. Mattila et al. (2010) reported that of the three young people in their sample with MDD, one also had comorbid anxiety disorders, conduct disorder, oppositional defiant disorder and motor tics. One young person was also diagnosed with a comorbid specific phobia

and the third also diagnosed with ADHD. Mukaddes and Fateh (2010) reported that of the 11 young people diagnosed with MDD, 55% were also diagnosed with an anxiety disorder, 27% were also diagnosed with ADHD and 36% were diagnosed with two or more comorbidities, in addition to depression. Additionally, Wilson et al. (2014) reported that diagnostic status for ADHD accounted for 3% of the variance in depression symptoms, ADHD symptoms accounted for 8% of the variance in depression symptoms and the interaction between status and symptoms accounted for 6% of the variance, with children with higher levels of ADHD symptoms experiencing greater depressive symptoms.

*Medication:* seven of the studies reported that the young people in their sample were on psychoactive medication, and in some cases receiving outpatient care from a psychiatrist (three studies) or counselling (one study). The rates of medication use ranged from 75% (Joshi et al., 2014) to 5% (Green et al., 2000) for medication described as psychoactive or affecting emotional functioning, which included both antidepressants and mood stabilisers. Only Strang et al. (2012) investigated the effect of medication use, repeating their analysis excluding those on medication, and finding no change in their results. Strang et al. (2012) further reported that 40% of those on medication still reported levels of depression in the clinical range. Mazefsky et al. (2011b) specifically asked participants to consider the time prior to starting medication during their interviews.



### *Quality*

Overall the quality of the papers was poor to moderate, with the highest rated paper, Mattila et al. (2010), only scoring 19 out of a possible 24, and the lowest rated paper, Whitehouse et al. (2009), scoring 9 out of 24. It should be noted that the quality criteria were designed specifically for this review and that Whitehouse et al. (2009) did not have the primary aim of investigating the prevalence of depression. The identified weaknesses were broadly similar across the studies. Apart from two studies, (Mattila et al. (2010) who screened a large population of 4,422 children for ASD, and Hebron and Humphrey (2014) who provided information about the study to all young people with ASD in 17 secondary schools), the majority of studies relied on either convenience samples recruited from clinical settings or self-selected samples who responded to adverts placed in clinical environments and support groups. Over half of the studies did not report the dates for recruitment and the majority of the studies did not report their sample size relative to the number potentially eligible or the number of participants excluded. All but one study used measures of depression that did not have established psychometric properties for use with people with ASD. Six studies relied only on a prior diagnosis, non-standardised clinical interview, or screening tool to confirm the diagnosis of ASD. While the majority of studies reported some possible confounders, such as other comorbidities and medication, only a minority considered the effect these might have on their results (for coding of quality see Appendix 3).

### **Discussion**

This systematic review aimed to explore the prevalence of depression in children and young people with HFASD. The reported prevalence in the papers included in this

review varied from 0% (Giovinazzo et al., 2013) to 83% (Mazzone et al., 2013). It is likely that this variability can be explained by the different methodologies employed and variation in quality. A direct comparison of these findings with the literature on typically developing children and young people is difficult. This is due to these findings being primarily based on community samples in contrast to the mixed clinical and education samples included in this review. In a review of the prevalence of depression in typically developing children and young people Avenevoli et al. (2008) reported current prevalence rates varying from 1% to 13% and lifetime prevalence rates varying from 4% to 24%. These rates are lower than the majority of those reported in this review. However, it should be noted that Avenevoli and colleagues (2008) only included studies which used interview based assessments of depression. Four of the papers included in this review (Hebron and Humphrey, 2014; Mazzone et al., 2013; Whitehouse et al., 2009; Wilson et al., 2014) also reported prevalence rates for a typically developing comparison group. All reported significantly higher rates of depression in the young people with ASD (range 0% to 40% in typically developing controls, range 3.2% to 83.3% in young people with ASD).

#### *Assessment of depression*

Assessment of depression in children with HFASD is complicated due to the core features of the disorder, both making it more difficult for children to self-report symptoms and masking observable symptoms (Kanne et al., 2009). Furthermore, there is no ‘gold standard’ assessment tool for depression in children with ASD (Magnuson and Constantino, 2011). Two measures have been developed to

specifically assess comorbidity in children with ASD: the ACI (Leyfer et al., 2006) and the Autism Spectrum Disorders-Comorbid for Children (ASD-CC) (Matson and Wilkins, 2008). However, the ASD-CC does not provide a sub-scale for depression which is separate from worry, therefore no studies using this tool met the inclusion criteria (Hess et al., 2010).

The greatest degree of variability was found in studies which relied on self-report in the form of responses to questionnaires or rating scales. These measures were designed for the typically developing population where it is assumed that children can provide an accurate report on their emotions (Witwer et al., 2012). It has also been highlighted that many of the items on self-report measures for depression can be sensitive to the symptoms of ASD (Matson and Wilkins, 2008). Therefore, it can be difficult to determine if scores on these measures reflect a comorbid disorder or symptoms of ASD (Mazefsky et al., 2011a). It should be noted that higher and more variable rates of depression have also been reported in the typically developing population using self-report measures when compared to interview based assessment (Kessler et al., 2001).

Mazefsky et al. (2011b) compared their findings using the ACI to the CDI and found that none of the young people meeting the diagnostic criteria for depression on the ACI met the threshold for depression on the CDI. The only other study to include both a semi-structured interview-based assessment (the K-SADS) and a questionnaire (the CDI) was Giovinazzo et al. (2013). Unfortunately, Giovinazzo et al. (2013) do not report who was involved in the K-SADS or report results separately for the two measures, making it difficult to draw meaningful conclusions from their results. Mazzone et al. (2013) also included two measures of

depression, the CDI and the CDRS-R, finding different results between the two measures. Although both are questionnaire-based and completed by the child, the CDI was self-administered while the CDRS-R is a rating scale administered by clinicians in the form of an interview. Furthermore, Mazzone et al. (2013) stated that 'if necessary' (p3701) the CDRS-R was also administered to adult informants, but did not provide further details.

Several studies on depressive symptoms in children with ASD have shown that the informant used can have a significant effect. Using the CBCL in a sample which included some young people with HFASD, Kanne et al. (2009) found that parents reported higher rates of affective problems compared to teachers (26% and 6% respectively). Of the papers included in this review, only Wilson et al. (2014) used teachers' reports; however, it is notable that this was one of the lowest prevalence rates reported. Vickerstaff et al. (2007) only reported the percentage of young people reaching the clinical cut-off for depression based on self-report using the CDI. However, they also reported mean teacher and parent scores based on the BSAC, where they found that mean teacher ratings were in the 'at risk' range compared to mean parent ratings in the 'clinically significant' range and mean child ratings in the 'average' range. Lopata et al. (2010) also included children's self-report in addition to parents' report, but did not report the percentage meeting a clinical cut-off. They reported that the mean self-reported score was in the average range, while the mean parent-rated score was in the at-risk range.

This suggests that caution is warranted in interpreting findings based on the report of one informant using questionnaires which were developed for the typically developing population. In contrast to this, the most consistent results were from

semi-structured interviews which were administered to both the children and parents. Although this consistency does not necessarily mean the results are more accurate, it does suggest that they are more reliable. However, it is not always clear if in those studies interviewing both children and parents the interviews were conducted separately, and how the results were combined to provide the diagnostic status.

### *Characteristics of the samples*

It has been suggested that samples derived from clinical settings, as the majority of samples included in this review were, might overinflate the presence of psychiatric comorbidities (Green et al., 2000). Contrary to this, the two samples in this review which recruited only from educational settings (Hebron and Humphrey, 2014; Whitehouse et al., 2009) had some of the highest rates of depression (36.4% and 65.7%), although it should be noted that both of these studies also used self-report measures of depression. Furthermore, Mattila et al. (2010), who included a sample derived partially from a general hospital population and partially from a large community sample that was screened for ASD, found current rates of depression at the lower end of those reported (6%) using the K-SADS. Joshi et al. (2014) found higher rates of depression in a sample recruited from a general psychiatry setting compared to an ASD specific clinic. However, only the sample from the general psychiatric clinic met the inclusion criteria, as the ASD clinic sample comprised of a mixture of young people with HFASD and those with an LD. Young people with HFASD may be at particular risk for depression and therefore this may also explain the difference between the two samples. However, it does suggest that where the sample was recruited from needs to be carefully considered. This can be difficult, as

many papers include samples from a mixture of settings without reporting the relative contributions of different settings or if there was a difference in rates of depression between the settings (Lopata et al. (2010); Wilson et al. (2014); Witwer and Lecavalier (2010) included in this review).

Only one study in this review found an association with age, and multiple studies failed to find an association. One explanation for this is that the majority of studies had a mean age between 9 and 12 years, with the oldest mean age being 14.2 years. In the typically developing population the prevalence of depression is lower in children aged 7 to 12 (point prevalence's of 1% to 2%) compared to adolescents aged 13 to 18 (point prevalence's of 1% to 7%) (Avenevoli et al., 2008). Only one study included in this review (Whitehouse et al., 2009) included a sample with a mean age in the adolescent range. This was one of the higher prevalence's reported (65.7%); however, they also assessed depression using a questionnaire based measure completed by the young person. Therefore, it is possible that for an effect of age to be found more consistently, studies need to include older adolescents. Similarly, previous research has suggested that girls with ASD may experience higher rates of depression than boys with ASD (Solomon et al., 2012). Furthermore, in the typically developing population during adolescence (although not preadolescence) depression is more common among girls (Avenevoli et al., 2008). However, the only study to include a sufficient number of girls to address this (Solomon et al., 2012) did not meet the inclusion criteria, as young people with a prior diagnosis of depression were excluded.

A further factor which is likely to contribute to the variation in prevalence of depression is the prevalence of other comorbidities, such as anxiety disorders and

ADHD. It would appear that studies with higher rates of other comorbidities, in particular ADHD, are associated with higher rates of depression. This could reflect the greater difficulties experienced by young people who have to manage the symptoms associated with multiple disorders simultaneously. However, it could also reflect differences in measurement, with studies using stricter criteria or tools to assess depression also using stricter criteria for other comorbidities. In support of the first hypothesis, in those studies that provided data on the overlap between comorbidities, the majority of young people with depression also had other comorbidities including anxiety disorders and ADHD (Mattila et al., 2010; Mukaddes and Fateh, 2010). Furthermore, Wilson et al. (2014) and Gadow et al. (2012) have demonstrated that young people with ASD and comorbid ADHD symptoms have higher depressive symptoms than those without comorbid ADHD.

The majority of children with ASD are prescribed either anti-psychotics, antidepressants or medication for ADHD symptoms (Logan et al., 2014). Despite this, less than half of the studies included in this review reported if their participants were taking medication and only two studies (Strang et al., 2012; Mazefsky et al., 2011b) considered this in the analyses. Only studies recruiting from a clinical setting reported medication use; however, studies from other settings do not report an absence of medication use. As Mazefsky et al. (2011b) highlight, this limitation is hard to avoid as it would be unethical to ask participants to stop helpful medication. However, it raises questions as to whether the reported rates of depression are significantly under-representative (if the medication is effective) or if the prescribed anti-depressants are ineffective given the high rates of depression reported.

### *Strengths and weaknesses*

Strengths of this review include the rigorous search strategy used and the narrow focus on only depression and only children with HFASD, which allowed for a detailed examination of relevant issues. However, a limitation of this review is the quality of the studies eligible for inclusion. In order to gain as broad an understanding as possible, no attempt was made to exclude studies based on quality; however, this means that some of the results presented are from relatively poor quality studies. This has meant that in many instances it was not possible to draw definitive conclusions.

Quality was assessed using quality criteria specifically designed for this review, which, in line with the recommendations of Sanderson et al. (2007), were developed using STROBE reporting criteria (von Elm et al., 2007) as a starting point. However, it should be highlighted that some authors have concluded that it is inappropriate to use STROBE to assess quality, as STROBE criteria are reporting guidelines. Reporting quality (assessed by STROBE) is not equivalent to methodological quality (da Costa et al., 2011). In contrast to this, Sanderson and colleagues (2007) argue that many of the STROBE items were selected due to ‘association with susceptibility to bias’ (p674), which is a key factor in assessing the methodological quality of a study and that no previously developed tool can be recommended as a gold standard. Furthermore, to reduce the potential for the rating of quality to be unduly influenced by the quality of reporting, the criteria relating to the introduction and discussion were not included and additional quality criteria, relating to sampling, were incorporated from the quality criteria developed by Shamliyan et al. (2011).



A further potential weakness is that studies with a primary aim of understanding prevalence as well as those with other aims were included. Therefore, some of the studies were not designed to address the methodological issues associated with prevalence, which is reflected in low quality scores. Furthermore, no attempt was made to distinguish results based on young people diagnosed with AS compared to those with other diagnoses. This reflects the changes to diagnostic criteria in which this distinction is no longer considered theoretically important (Lord and Jones, 2012). However, this change is still debated and it is possible that the different diagnoses included may have affected the results (Ghaziuddin, 2010; Turygin et al., 2013).

Furthermore, this review has focused only on those young people with ASD who scored above clinically significant cut offs on self-report questionnaires, or who met the criteria for depression when assessed using semi-structured interviews primarily based on DSM-IV criteria. Within the literature on typically developing children it has been highlighted that young people with depressive symptoms that do not meet diagnostic thresholds still experience significant functional impairment and seek treatment (Avenevoli et al., 2008). Thirty-one studies were excluded from this review because they measured depressive symptoms but did not report that number or percentage reaching a clinically significant cut-off. As already discussed, these studies still provide useful insight into the impact of factors such as how depression is measured and relates to gender. Additionally, some authors have argued that for typically developing children the line at which normal or appropriate emotion is divided from clinical depression is unclear (Shearer and Bermingham, 2008; Timimi, 2004). Given the difficulties assessing depression in children and young people with

ASD, this is likely also to be an issue in this population. Furthermore, it has been argued that labelling a young person with depression pathologizes what may be an understandable reaction to a difficult situation and risks increasing stigma (Carr, 2006). However, it has also been argued that diagnosis is necessary to allow for the development of evidenced based treatments and to make decisions about intervention which are evidence based (Carr, 2006). This is particularly important in young people with ASD where there is a risk of all difficulties being attributed to the ASD itself rather than depression, which has implications for intervention (Matson and Williams, 2014; Magnuson and Constantino, 2011). Carr (2006) argues that classification of psychological difficulties is particularly useful as it allows for epidemiological information, such as the prevalence rates in this review, to be established, which in turn allows for the planning of services.

Finally, all findings are based on observed trends only and no attempt was made to statistically combine the results from the different studies, or to statistically examine the impact of the factors explored on the prevalence of depression. In their review of anxiety disorders in children and young people with ASD van Steensel et al. (2011) used moderator analysis to explore the impact of factors such as mean age and whether questionnaires or interviews were used on prevalence. However, Lipsey (2003) highlights the difficulty and often inappropriateness of this type of analysis when the potential moderator variables are related not just to effect sizes (or in this case prevalences) but also to each other. He argues that interrelatedness among potential moderators can lead to statistical confounding, which limits the potential to understand the role of any one moderator. This significantly limits the potential for the use of meta-analytical techniques to test the hypothesis generated by this review

about the reasons for the high level of variation in the reported prevalences. As already discussed, the potential variables considered by this review are all interrelated, for example, with the type of informant being related to the type of assessment (interview or questionnaire) and the potential for the prevalences of comorbid ADHD to be related to the assessment criteria or method.

### *Conclusion*

In conclusion, rates of reported depression varied, with some studies reporting very high prevalence rates of above 40% and others much lower prevalence rates of 5% and below. There was greater variability in those studies which relied on self-report from questionnaire-based measures and more consistency in those studies using semi-structured interviews and combining children's self-report with parental report. It is likely that variable recruitment strategies and rates of other comorbidities, particularly ADHD, affected the results. However, further research is needed to better understand the relative impact of these factors and how depression can be reliably assessed in children and young people with HFASD.

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# **Chapter 2: Exploring transition to adulthood from the perspectives of young people with high functioning autism and their families**

## **Abstract**

The transition to adulthood is characterized by significant changes to both services and daily routines. People with High Functioning Autism Spectrum Disorders (HFASD) have significant difficulty with any changes to their normal routine. This study explored transition from the perspectives of four dyads of young people with HFASD attending mental health services and their mothers. Transition to adulthood was described as a process during which the young person is developing independence, while parents continue to have a role in providing support. Current and future support needs were perceived differently by young people and their parents, with young people perceiving less need for support. Further research is needed to explore the generalizability of these findings.

**Key Words:** transition to adulthood, HFASD, CAMHS, support needs

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## **Introduction**

Autism Spectrum Disorder (ASD) is characterised by difficulties with social interaction and communication and restricted or repetitive behaviours and interests (Lord and Jones 2012). ASD is typically diagnosed in childhood, and any identified behavioural difficulties usually lessen over the course of childhood and adolescence (Taylor and Seltzer 2010). However, for people with High Functioning Autism (HFA) or Asperger Syndrome (AS) (which are characterised by the absence of a Learning Disability (LD) and collectively referred to as High Functioning Autism Spectrum Disorders (HFASD)), this improvement slows significantly after leaving school, and adults with HFASD still experience significant difficulties with everyday life (Taylor and Seltzer 2010; Griffith et al. 2012).

People with ASD have significant difficulty with changes to their normal routines and struggle with situations which are unpredictable or involve meeting new people (McConachie et al. 2011). These difficulties become particularly problematic when a person with ASD has to make the transition to adulthood, which involves transitioning from services for children to services for adults, and from school to adult life (McConachie et al. 2011). This involves many changes, with young people often having to adapt to new environments for work or further education (Smith et al. 2012). Transition to adulthood is particularly difficult for those young people with ASD who have additional emotional or behavioural difficulties which require support from child and adolescent mental health services (CAMHS) (Singh et al. 2010). A recent study by Singh et al. (2010) followed the progress of 154 young people who were receiving support from CAMHS after they were discharged. They

reported that the 38 young people with neurodevelopmental disorders, including ASD, were the most likely to not be transferred to adult mental health services (AMHS). Some young people with ASD may instead transfer to community teams for people with learning disabilities; however, those with HFASD will not be eligible for this support (Griffith et al. 2012).

These transitional challenges were reported to be the result of different referral criteria between AMHS and CAMHS, with children's services focusing on behavioural difficulties and risk of harm while adult services are based around mental health diagnoses (Hovish et al. 2012). However, it should be noted that Singh and colleagues (2010) included only a relatively small sample of young people with neurodevelopmental disorders and do not report how many of these young people had a diagnosis of ASD. Furthermore, they do not provide details of the reasons young people with neurodevelopmental disorders did not transfer to AMHS separately from the full sample of 154 young people, who were being seen within CAMHS for a wide range of reasons. It is possible, although unlikely, that a majority of those with neurodevelopmental disorders who did not transfer to AMHS had no further need for mental health service in-put.

Rates of mental health diagnoses, particularly anxiety disorders, which would result in a young person being eligible for support from AMHS, are high in people with HFASD (van Steensel et al. 2011). However, assessment of comorbid mental health problems is a challenge in adolescents with ASD due to the overlap between symptoms of ASD and those of anxiety and depression and difficulties with communication (Leyfer et al. 2006). Furthermore, levels of subclinical mental health problems, which would not meet the criteria for AMHS, are very high, with Mayes et

al. (2011) reporting that 89% of 11 to 17 year olds with HFASD experience anxiety symptoms and 72% experience depression symptoms.

Additionally, young people with HFASD often continue to need support with communication problems and the social elements of further education or employment (Griffith et al. 2012). However, within the UK and most other countries, this support is often unavailable (Griffith et al. 2012; Moxon and Gates 2001). This may partly explain why rates of employment are typically low in people with ASD (Holwerda et al. 2012). It has been suggested that this lack of support and opportunities, compounded by an awareness that their progress is different to their peers', may have a detrimental effect on the mental health of people with HFASD (Moxon and Gates 2001). Although it should be noted that this association has not been tested empirically. This is particularly problematic if it is occurring at a time when young people are no longer receiving support from mental health services. Furthermore, it has been highlighted that, even for those young people who are eligible for adult mental health services, transition is often characterised by a lack of coordination between CAMHS and AMHS, resulting in a high risk of disengagement from services (Singh et al. 2010; Singh 2009).

Transition not only results in changes for young people but also for their families. Hovish et al. (2012) explored transition from CAMHS to AMHS qualitatively in a study which included interviews with six parents. They reported that after transition parents are much less involved in their child's care and often want greater involvement than services allow. Cadman et al. (2012) investigated the burden on carers of 87 young people with ASD and 86 young people with Attention Deficit Hyperactivity Disorder (ADHD) who were aged 14-24 and at various stages

of transition out of CAMHS. They reported high levels of caregiver burden for both groups; however, it was significantly higher in those caring for someone with ASD. Furthermore, levels of burden were significantly correlated with parents' perceptions of unmet need (Cadman et al. 2012). High levels of stress and negative emotions in families have been found to affect not only the wellbeing of parents, but also to increase the intensity of ASD symptoms in the young person (Smith et al. 2012).

Despite the difficulties people with ASD are likely to experience with transition, very little research has investigated transition for this population. Swift and colleagues (2013) included two young people with ASD and comorbid ADHD as part of a qualitative study involving a total of 10 young people with ADHD. Hovish and colleagues (2012) interviewed 11 young people who had previously attended CAMHS, one of whom had ASD. These studies highlighted that transition can be complicated by changes in the young person's social situation, and the need for multi-agency working and joint working between CAMHS and AMHS. However, the conclusions of both these studies are based on small sample sizes recruited from limited geographical areas. Furthermore, Hovish et al. (2012) only included young people who had, at least initially, been transferred to AMHS. As already highlighted, this outcome is less likely for the majority of young people with HFASD and therefore it is not clear how transferable these findings are to this population. The young people interviewed by Swift et al. (2013) all had neurodevelopmental disorders and the majority had already been discharged or were still in CAMHS. Therefore these results may be more generalizable to the experiences of young people with HFASD. However, it should be noted that seven of the 10 interviews were conducted with a parent present. Meaning that opportunities to explore any

differences in the experiences or perceptions of young people compared to their parents were limited. Additionally, Swift and colleagues (2013) suggest that future transition research should focus on individual conditions and Swift and colleagues (2012) and Hovish and colleagues (2012) only include 3 young people with ASD in total. Research focusing on the specific needs of people with ASD is very limited and, therefore, much needed. This study expands on the previous literature by focusing specifically on young people with HFASD and explores the similarities and differences between the experiences of young people and their parents.

### *Aims*

People with HFASD are in a unique position to describe the difficulties they experience (Griffith et al. 2012). Given the high caregiver burden during transition and its relationship with unmet need, it is also important to gain an understanding of families' perceptions of the transition process. Therefore, this study aimed to explore transition to adulthood for young people with HFASD who currently attend CAMHS from the perspectives of both young people and their families. Particularly, this study aimed to understand the impact of this transition on young people and their families and what support, if any, young people with HFASD and their families need during this transition.

## **Methods**

### *Design*

This study employed a qualitative design in which data collection and analysis followed the principles of Interpretative Phenomenological Analysis (IPA), as

described by Smith et al. (2009). Qualitative approaches are particularly useful when trying to understand the often complex process of transition and its impact on young people (Swift et al. 2013). IPA was chosen for this study as it allows for the understanding of people's life experiences and is particularly useful for understanding how individuals interpret major life events, including transitions (Smith et al. 2009). IPA has been used effectively to explore other transitions that occur in everyday life, such as the transition to motherhood and migration (Smith et al. 2009), and to understand the experiences of people with ASD and their families (Griffith et al. 2012; Cridland et al. 2014). This study was also multi-perspective, involving dyads of young people and their parents. IPA has been used in similar studies to explore both the similarities and differences in the experience of the sample of interest and their carers (Clare 2002; Smith et al. 2009; Cridland et al. 2014). IPA is particularly useful for understanding the experiences of dyads, as it combines a focus on the unique idiosyncratic features of an individual's experiences with an exploration of shared similarities and differences between the participants. This focus allowed for an understanding of the experiences shared across the whole sample (both young people and parents), a comparison of the similarities and differences within each dyad, and a broader comparison between the collective experiences of the young people and collective experiences of the parents.

### *Participants*

Participants were recruited using purposive sampling, a method of non-probability sampling in which participants are deliberately chosen to allow a specific topic to be explored in detail (Ritchie et al. 2003). For this study, the criteria used to select

participants were that they have a diagnosis of a HFASD, were aged between 14 and 18 years and currently attended CAMHS. This age group was chosen as it has been proposed that transition planning should start at age 14. Each young person was asked to nominate one parent or person with parental responsibility to take part in the study. In all cases the young people nominated their mothers. IPA uses a case-by-case analysis, which requires a homogenous sample, where all participants have a meaningful experience of the phenomenon under investigation to allow patterns within the data which are specific to the research question to be explored (Smith et al. 2009). For these reasons, IPA samples are typically small, with Smith and colleagues (2009) recommending the use of three to six participants. Five young people and their mothers agreed to take part in this study; however, over the course of the interview, one mother reported her belief that her child has a LD and would be transitioning to the community team for adults with LD. This dyad was therefore excluded from analyses, leaving four young person-mother dyads. One mother asked her mother (the young person's grandmother) to be present during her interview as she has a significant role in supporting the young person. The young person also agreed to this and therefore the total sample size was nine: four young people and five people with parental responsibility. Details of the four dyads are presented in Table 1. This sample size is consistent with previous research using IPA to understand the experiences of young people with ASD and their families and allowed in-depth analyses of each dyads' experiences (Cridland et al. 2014).

Table 1: Relevant information about current education, service involvement and family composition.

<b>Young person's pseudonym (age)</b>	<b>Current education/employment</b>	<b>Current CAMHS involvement</b>	<b>Other service involvement</b>	<b>Mother's pseudonym</b>	<b>Family composition</b>
Mark (17)	school (S6), planning to go to college away from home next year	psychology, appointments every 4 to 6 months	some school support, speech and language therapy stopped 2 years ago, employment services agency	Jill	Mother, Father, older Brother
Jamie (18)	college and part time job, unsure about next year	psychology, appointments every 5 or 6 months	support in college, employment services agency	Sandra	Mother, Father, older Brother
Michael (16)	school (S5), planning to go to university away from home after S6	psychology and psychiatry	school support including autism specific education service, transition social worker	Mary	Mother, Father, younger Sister
Fiona (18)	college, planning to stay at college for at least 1 more year	psychology, appointments every 6 months at time of recruitment but had been discharged prior to interview	support in college, transition social worker	Jane (mother) Sheena (grandmother)	Mother, Father, Grandparents also living in family home



### *Procedure*

Ethical approval was granted by the NHS National Research Ethics Committee, North of Scotland (Appendix 5). Young people were recruited via professionals working in CAMHS, who were asked to provide information about the study to all young people who met the inclusion criteria. The information provided prior to the interviews included the aims of the study and potential discussion topics. Young people who were interested in taking part provided contact details and were then approached by the researcher. Each young person was asked to provide contact details for a parent or person with parental responsibility who was then approached separately by the researcher. Participants were only included if both the young person and their nominated parent provided individual written informed consent. Data collection involved semi-structured interviews, which were conducted separately with the young person and their nominated parent, at a place of the participant's choosing. Two young people and one parent were interviewed in the local CAMHS building and two young people and three parents, were interviewed in their home.

Semi-structured interviews are commonly used within IPA studies, as they allow for sufficiently detailed data to be gathered. Furthermore, in an interview the researcher is able to adapt the questions in response to areas raised by participants, which provides greater opportunity for participants to provide their individual account of the research subject (Smith et al. 2009). The interviews followed a topic guide (Appendix 10) which included open-ended questions about the support the young person currently receives, their perceptions of transition, including any areas of concern, and their expectations of life and services after they leave school and

CAMHS. The interview guide was applied flexibly to facilitate a detailed exploration of transition without prior assumptions of areas that might be important to young people and their parents. All interviews were conducted face-to-face, audio recorded and transcribed verbatim by the researcher. Interviews with the young people lasted on average 34 minutes (range 24 – 48 minutes) and the interviews with parents lasted on average 39 minutes (range 30 – 46 minutes).

IPA actively acknowledges the researcher's own role in interpreting experiences through the accounts of participants, who are themselves making sense of what is happening to them (Smith 2011). In this research, the researcher has significant experience, both clinical and familial, with adolescents with HFASD. Smith and colleagues (2009) discuss the importance of reflecting on previous knowledge of the area of research to increase awareness of any preconceptions. According to Smith and colleagues (2009) it is important to engage in this reflective process both prior to starting the research and throughout data collection and analysis, as the researcher may not be aware of all of their preconceptions. In this study it was acknowledged prior to starting that the researcher's interest in this topic was partially driven by her previous experience researching transition to adulthood in a physical health population. This research had brought with it considerable awareness of the literature, in which transition is generally presented as a negative experience with many potential difficulties. Discussion with supervisors and reflection on the significant limitations of the previous literature (particularly the absence of research from the perspectives of young people themselves) was used to 'suspend or bracket off' (Smith et.al. 2009 p42) these preconceptions to promote an open-minded approach to the research. An additional area of discussion was the

researcher's role as a Trainee Clinical Psychologist. This role meant that the researcher had experience working in all mental health teams in the local area, including CAMHS, AMHS and LD services. This brought with it an awareness of the services likely to be available to the young people taking part in the study after leaving CAMHS. The researcher was also aware of on-going perceptions among mental health staff that transition is a difficult experience, often resulting in a reduction of available support. Supervision (including supervision with a Clinical Psychologist also working in CAMHS) was used to facilitate the 'bracketing' of this knowledge during the interviews and analysis. Furthermore, prior to the interviews, participants were informed of the researcher's status as a clinician within CAMHS and made aware of the difference between research interviews and a clinical appointment. It was explained that the researcher was interested in their experiences and was not in a position to offer information or advice.

### *Analysis*

When using IPA, analysis involves engaging in a double hermeneutic in which the researcher attempts to 'make sense of the participant trying to make sense of what is happening to them' (Smith 2011, p10). Analysis was conducted following the principles described by Smith and colleagues (2009), which involved five steps:

1. The researcher immersed herself in the data, first by transcribing the audio files and then reading and re-reading the transcripts while listening to the audio files.
2. Each transcript was explored in detail, with comments and observations for both the descriptive content and possible meaning noted for each line of transcript.

3. Emergent themes were noted using both the original transcript and the comments from step two. These themes incorporated both the participant's original words and the researcher's interpretation.
4. Connections between these themes and clustering and structure of themes were explored. Mind-maps were created including all the emergent themes to facilitate understanding of how the themes clustered to establish super-ordinate themes. In line with the method described by Clare (2002), who also included care-giver accounts, following step four, the corresponding parent transcript was analysed following the same process. Each young person's account and the themes identified were then individually read alongside the parent's account, and any similarities and differences and themes emerging noted. Steps one to four were completed for each dyad before moving onto the next dyad.
5. The themes and connections from all the dyads were brought together to understand both similarities and differences across the participant's experiences and to allow for greater levels of interpretation. As part of this process, a combined set of super-ordinate themes and sub-themes was created reflecting the themes from all interviews. Each transcript was then reviewed to confirm that this structure of themes accurately reflected the original analysis from steps one to four.

Dedoose, qualitative data management software ([www.dedoose.com](http://www.dedoose.com)), was used to facilitate coding of the data for themes and the process of integrating themes across the dyads, in addition to providing an audit trail of the analysis. Quality was maintained during the analysis by following the guidelines detailed in Smith (2011). These guidelines include the recommendation that each theme is supported by

extracts from at least half of the participants, elaborated sufficiently and that analysis has an interpretative focus. In this study this was considered to be either half the participants (both young people and parents) or two young people or two parents. In line with the recommendations of Smith et al. (2009), supervision, including reviewing of subsets of coding by researchers experienced in the use of IPA, and a reflective log (appendix 11) were utilised. These processes facilitate reflexivity during the analytical process by allowing active acknowledgement of prior perceptions. According to Smith et al. (2009) this serves two functions; first it assists the researcher in ‘bracketing’ both their own preconceptions and their knowledge from the analysis of one transcript as they move on to the next. This aims to minimize potential bias and allows for the focus to remain on making sense of that person’s experience. Second it allows for reflection on personal experience to assist the analytical focus of IPA.

## **Results**

Five super-ordinate themes were identified which were reflected in all the interviews: becoming an adult means developing independence, changing role and experience of families during transition, current and future support needs, what it means to have ASD and further education as a positive change. A further 24 sub-themes were identified, which were each present in over half the interviews (see Table 2 for full details and distribution of sub-themes).

Table 2: Distribution of super-ordinate themes and sub-themes across participants (all super-ordinate themes were present in all interviews).

Super-ordinate themes Sub-themes	Dyad 1		Dyad 2		Dyad 3		Dyad 4	
	Parent (Jill)	Young Person (Mark)	Parent (Sandra)	Young Person (Jamie)	Parent (Mary)	Young Person (Michael )	Parent (Jane)	Young Person (Fiona)
<b>becoming an adult means developing independence</b>								
young person taking responsibility for their own support	✓	✓	✓	✓	✓	✓	✓	✓
young person making decisions about further education	✓	✓	✓	✓	✓	✓	x	✓
young person learning skills to be independent	✓	x	✓	✓	✓	✓	✓	✓
importance of social interaction and friendships	✓	✓	✓	✓	✓	✓	✓	✓
young person developing self-reliance and managing difficulties independently	✓	x	✓	✓	✓	✓	x	✓
<b>changing role and experience of families during transition</b>								
supporting young person has an impact on family	✓	x	✓	x	✓	x	✓	x
family as a source of support and advice	✓	✓	✓	✓	✓	✓	✓	✓
parent's role in facilitating transition and access to support	✓	✓	✓	✓	✓	✓	✓	x
family have worries about the future and independence	✓	x	✓	x	✓	✓	✓	x
<b>current and future support needs</b>								
importance of enhanced transitions	✓	✓	✓	✓	✓	✓	✓	✓

roles and remits of mental health services, education, employment services and social work	✓	✓	✓	✓	✓	✓	✓	✓
support should be 'background' support which is not intrusive	✓	x	✓	✓	✓	✓	✓	x
perceptions about the availability of support	✓	x	✓	x	✓	✓	✓	x
reduction in need for support with age	✓	✓	✓	✓	✓	✓	x	x
difference between young person's and parents' perceptions of needed support	✓	✓	✓	✓	✓	✓	✓	✓
<b>what it means to have ASD</b>								
multiple changes as a potential difficulty	✓	✓	x	✓	✓	✓	✓	✓
understanding/ awareness of core symptoms	✓	✓	✓	✓	x	✓	✓	✓
need for people to be understanding/ aware of difficulties	✓	x	✓	x	✓	✓	✓	✓
how ASD is perceived	✓	x	✓	✓	✓	✓	✓	x
normal transition compared to transition in ASD	✓	x	✓	✓	✓	✓	✓	x
<b>further education a positive change</b>								
further education as an opportunity to socialise	✓	✓	✓	✓	x	✓	✓	✓
although a positive still some concerns	✓	✓	x	✓	✓	✓	✓	✓
uncertainty about life after college	✓	x	✓	✓	x	x	✓	✓
further education as a practical decision	✓	✓	✓	✓	✓	✓	✓	x

### *Becoming an adult means developing independence*

All participants described an important part of the transition to adulthood as the young person developing independence. Five sub-themes were identified which reflected the different aspects of this process: the young person taking responsibility for their own support, the young person developing self-reliance and managing difficulties independently, the young person making decisions about further education, the young person learning skills to be independent and the importance of social interaction and friendships. All participants described a process in which the young person was starting to be involved in, and take responsibility for, their own support, for example by attending appointments alone, making decisions about what support is needed and communicating when they need support.

*Jamie: It's been my parents and the helpers kind of driving that [support] but I think I'm kind of at the stage now where, like I said, I'm taking things into my own hands, I'm trying to deal with the situation and I think that's kind of working out.*

*Sandra: If he needs them again [employment services] he knows he can just contact them ... you know he can be supported but he doesn't need them all the time so he's kind of used that support and now he's comfortable in college so far and he's also comfortable with where he's at so far and if he's not he'll speak to the lecturers.*

For parents, the importance of the young person taking responsibility for their own support was linked to their feeling that the original process of receiving a diagnosis and accessing support had been led by them and had been their decision. Parents identified feeling that, now the young person was becoming an adult, future



decisions about support should either include the young person or be made exclusively by the young person. For young people it appeared to be associated with a desire to 'take things into my own hands', as described by Jamie. Young people also appeared, and were described by their parents as, reluctant to access support. This reluctance to be identified as needing support was described by parents as a barrier to the young person accessing support.

*Jill: Mark will need support I think, how that's going to take place I don't know because he, it's very difficult because he doesn't like to think that other people are looking round and seeing that he needs support ... it's a difficult one, because it's what Mark will accept because he's then an adult and we can't put that there, he has got to be able to do it on his own.*

Three out of the four young people also expressed uncertainty about how support was organised and provided, and what support might be available, or what they might need as an adult. Three of the young people and all the mothers highlighted the need for young people to develop skills to manage any difficulties without support. This included learning to use strategies to manage difficulties such as anxiety, and developing self-reliance and confidence. Transition was also described as a time during which the young person learns the skills they need to be independent, including daily living skills and driving. Although all young people were described to be developing some level of independence, concerns around areas such as managing finances and the potential vulnerability of young people with autism were identified. Furthermore, opinions were mixed about how well the young

people would manage living away from their parents. Only one young person reported feeling confident about this, with three young people and all parents expressing some concerns.

*Jamie: I think the only real concern I would have was just would be moving out and taking matters into my own hands ... I'd have to become more responsible and self-aware rather than having all this reliability that I've had for ... the entire of my life.*

*Sandra: At one time I could never have seen him being very far away from us, not so sure about that now, because if the right support was in place you know he maybe could move on.*

Although some of these concerns are likely to be experienced by all young people, a diagnosis of ASD appeared to add an additional layer to this, with greater emphasis on the difficulty with change and the importance of 'reliability'. Parental accounts emphasised the need for support during this process. For example, Sandra qualified her statement with 'if the right support was in place'.

All young people and parents also identified transition as a time in which developing friendships becomes increasingly important. Moving towards friends as a source of support, instead of reliance on parents, was also considered to be an important part of becoming an adult, which could be difficult for young people with ASD and a concern for parents.

*Jill: Friends are something that come and go what have you, he tends not to contact people if they leave his social circle ... I think it is important because you need to*

*have friends to go and discuss things because if things aren't going right sometimes it's not your parents that you come and discuss it with, it's your friends.*

However, this was also identified as being something which improved with age.

*Sandra: I don't know where he'll end up but I'm less worried about him being on his own than I might have once been, he's now forming friendships.*

Furthermore, no young people described concerns about developing friendships, and three out of the four young people described their current friendships as important to them.

In contrast to the change in support, where young people expressed uncertainty, transition in education was characterised in the majority of interviews as a process led by the young person, in which the young person was actively making decisions. This process involved the young person spending time researching potential courses and what going to college or university would involve.

*Mary: Michael is driving this, Michael is doing a lot of research into university life, what it looks like, he's been watching a lot of videos, like YouTube things about what other students do.*

This difference between transition in terms of going to college or university compared to transition in terms of support may reflect the fact that going to further education is an aspect of transition that the majority of young people experience. In

contrast, changes in support and leaving CAMHS is something that only a minority of young people have to navigate. When discussing further education the young people in this study raised concerns about things such as writing a personal statement and getting good enough grades in exams. It would be expected that these are concerns experienced by most young people planning to attend further education and the sources of support discussed by the young people in this study (open days, peers, guidance teachers) are accessed by all young people. Therefore, the greater uncertainty and reluctance to access or be identified as needing ASD-specific support may reflect the fact that, unlike going to further education, this is not an experience that would be routinely discussed in school or shared with the majority of their peers. This may be a particular difficulty for young people with HFASD, who are educated in main stream settings where the majority of their peers would not have additional support needs. Furthermore, it was highlighted by some parents that peer support groups for young people with HFASD were not available in the local area. These young people would not have had the opportunity to discuss changes in support with other people in a similar position.

#### *Changing roles and experience of families during transition*

Although transition was characterised as a time during which young people developed independence, families still had a significant role in all accounts. Four sub-themes were identified as capturing this: the parent's role in facilitating transition and access to support, family as a source of support and advice, supporting the young person has an impact on the family, and family have worries about the future and independence. All parents described their role as being one of facilitating

transition and access to support, as well as providing the young person with support and advice. The role of parents in facilitating access to support was characterised by an awareness of the balance between promoting the independence of the young person and making sure that appropriate support was available.

*Jill: We can't always keep pushing because he will at present... just dig his heels in and he needs to be able to say right, I, yeah, I'll take that on board and go with it himself and it just keeps ..., we just keep on chipping away at it and encourage him to this and just keep on pushing him a wee bit as long as he's willing to be pushed slightly.*

This balance was linked to, and made more difficult by, an awareness that they would not always be around to provide support.

*Sheena: Her Mum and I are all getting older and you suddenly realise, you know, that we're not going to be here forever.*

This awareness that '*we're not going to be here forever*' also appeared to underpin the importance for parents that their child develops independence which, as already discussed, can be difficult for young people with HFASD.

As well as facilitating access to support, families were described as an important source of support and advice for decisions about the future, including further education, employment and managing finances. All young people valued the

support provided, and three out of four young people identified their parents as the main source of support available to them.

*Fiona: Well there's sometimes my parents ... they give me advice as well, what I'm gonna do with college, am I gonna leave or if I'm gonna stay.*

However, support from parents was also identified as limiting the potential for young people to develop independence and 'prove' to themselves that they can manage day to day skills such as managing finances.

*Michael: I suppose it's great having parents in that you have that sort of devil's advocate saying no that's a terrible idea and stuff like that and you'll do it and agree and it'll be the lack of that that I think I'll both enjoy and miss because I'll be proving to myself and making my own experiences and realising it's a good idea or not.*

Parents also highlighted their role in supporting young people by helping them to develop the skills needed for independent living, helping them adjust to change and promoting a sense of self-belief. In some cases this contrasted with the account given by the young person, for example Mary described her role in supporting Michael with finances very differently to him.

*Mary: So no matter what it is he's got to come to terms with he can generally do it but you have to be consistent for three months sort of before it so you know taking*

*control of own finances maybe giving him an account and that's what he does for three months so he's used to that bit.*

All parents described supporting a young person with autism as having an impact on them. However, although some identified that other families might need support, only one family identified any need for support themselves, and this was very specifically advice about how best to support the young person. Overall, parents described themselves as being able to manage as long as support was there for the young person.

*Jill: We've dealt with it all [his] days ... we've been fine but I know other people who probably do need but we've been fine because we have received support for him we haven't needed it because we've felt that ... it's all about him, it's not about us as long as he's been getting support to help him that's what it's been about, not support for us no.*

It is interesting to note that Jill also described her son, Mark, as reluctant to accept support, but for him this was characterised as a potential difficulty. This may reflect an underlying belief within the whole family about what it means to receive support. However, it may also reflect broader societal perceptions that it is the person with the disability that needs support or services, rather than the family or wider systems.

When the young person was not an only child, parents compared their involvement in the participant's life with their typically developing sibling. Although all described some similarities, all reported the young person with autism as needing

more support from them compared to their siblings. All parents also described either having had, or currently having, worries about the young person's future. These focused around how the young person would manage away from home, the potential for them to become isolated and how the young person is supported in the long term. For some parents these worries were in the past; however, others still had current concerns.

*Sandra: I'm not worried about it, I do think that things will fall into place although we don't know what they'll be, it doesn't worry me as much as it might have done three or four years ago 'cause I can see him moving on.*

*Jill: That is our fear that he goes, because there's actually a course he's looking at in [city] which is a big culture shock from where we live.*

Parents reported greater worries about transition and the future than the young people. This may be explained by the fact that, for parents, their current worries were related to times in the past when their child had experienced much greater difficulties. Mary, for example, described how in the past she was almost Michael's 'nurse' and being 'very very aware of how difficult things can actually be when he's unwell'. This awareness of the difficulties young people experienced in the past, together with an awareness of young people's reluctance to be identified as needing support, may explain parents' beliefs that they need to continue to facilitate access to support. It may also explain parents' perceptions that they will have to support their child to adjust to any changes and, as described by Jill, 'be there as the net that catches' in a way that they do not need to be for their typically developing siblings.



### *Current and future support needs*

Six sub-themes were identified which related directly to the support currently available and what support the young person might need in the future: difference between the young persons' and parents' perceptions of needed support, roles and remits of mental health services, education, employment services and social work, perceptions about the availability of support, reduction in need for support with age, importance of enhanced transitions and support should be 'background' support which is not intrusive.

The difference between the young persons' and parents' perception about what support the young person would need as an adult was directly addressed by one dyad and was identified as a theme in all comparisons between young people's and parent's' transcripts. Table 3 details how the young person and parental perceptions differed.

Table 3: Differences between parent's and young person's perceptions about the need for future support.

<b>Parent's beliefs about need for future support</b>	<b>Young person's beliefs about need for future support</b>
<i>Jill: continued support from psychology, support from college, employment support</i>	<i>Mark: support from college, not expecting to need further support from psychology</i>
'It would be fine to continue having input from somebody like what we've had here [referring to CAMHS] just to help him through this next stage because it is going to be a big step for him'	Researcher: do you think you'll need support from mental health services when you go to [college]? Mark: nah Researcher: why not? Mark: just dinnae think I would

<p><i>Sandra: support from college, continued support from psychology and employment services</i></p> <p>‘I do think if people are there and they’re offering certain things, for somebody like Jamie there’s never gonna be too much support’ ‘I think .... the psychologist route is definitely one that I would hope was to be continued and I do think the employment services’</p>	<p><i>Jamie: support from college, might need employment support, not expecting to need further support from psychology</i></p> <p>‘I’ve been with them [CAMHS] for some time so well, I say some time, I mean quite some time, so I already feel quite confident and self-reliant so I think I could cope pretty well without them’ ‘probably getting started on a big full time job, probably be a, it would probably be a yes, I probably, thinking about how I’ve been in the past, and how concerned I’ve been about certain prospects I probably would need some support’</p>
<p><i>Mary: continued psychiatry input and autism specific support from university</i></p> <p>‘...linking in with a psychiatrist, you know hospital so Michael can have sort of regular check-ins there too’ ‘the crux would be a an autism worker who had an overview but had the most enormous pair of boots to kick behind if necessary, that would be the ideal world finding you know an ally in that kind of scenario and it’s not to sort of go and cause trouble where it’s not needed but just to know exactly where to go you know if there are problems’</p>	<p><i>Michael: minimal support from university, continued prescription of medication</i></p> <p>‘I think I’ll certainly need support from the university... I do get extra time in all my exams which helps, yeah I suppose I could probably ask for that and I suppose slightly more understanding if I just seemed thick in not understanding something but I don’t suppose I really want any help’ ‘No I don’t think I really will [need continued support] and I, increasingly I find sometimes like the provision of support frustrating because it’s hindering me from being able to just be myself and be independent.’</p>
<p><i>Jane/ Sheena: continued psychology support, support with employment, support with independent living, support from college and social work</i></p> <p>Jane: ‘It would have been nice if we could have transitioned into someone similar [to clinical psychology] on the on the adult side even if it was one of the mental health care workers’ ‘we could probably do with an agency</p>	<p><i>Fiona: support through college, with academic work and understanding</i></p> <p>‘... sometimes help me ... with my maths or English like if one of my teachers talking too fast I don’t know what they’re talking about like ... they explain to me about slowly so I can understand’</p>

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somewhere that specialised in employment for young adults with disabilities.... and it's also knowing what they're entitled to about transport and maybe about learning to drive'

Sheena (grandmother): 'I think it would be social work more now.... psychology in-put as well'

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There appeared to be multiple reasons for this difference. First, as already discussed, parents had greater worries about the transition to adulthood and were more explicit about the difficulties young people had experienced in the past. It is unlikely that the young people would be as aware as their parents of any changes that occurred when the young person first accessed support, or difficulties they experienced before support was available. Additionally, young people expressed greater uncertainty about their current support and the organisation of support. Some of the young people seemed unaware of some of the services parents reported being involved, for example transition social workers. Therefore, young people's beliefs that less support will be needed as an adult may be linked to perceptions that they are currently receiving less support, or greater levels of uncertainty about their current support, than was reported by their parents.

It is notable that both young people and parents felt that the support they currently received had been beneficial. However, for parents this seemed to lead to the conclusion that this support should be maintained, while for young people it led to the conclusion that this had allowed them to develop to a point where they no longer needed support. For example, Jamie described how his previous contact with

CAMHS meant that he now felt *‘quite confident and self-reliant’* and therefore could *‘cope pretty well without them’*.

Furthermore, as already discussed, young people were reluctant to be identified as needing support, which may lead to a minimising of what support is needed. Additionally, some of the young people described previous negative experiences with support.

*Michael: Increasingly I find sometimes like the provision of support frustrating because it's hindering me from being able to just be myself and be independent ... in S3 we trialled with auxiliaries ... and they have a very sort of poor, probably just like the average layman's perception of autism and so on and they don't fully understand it and they over exaggerate how it sort of hinders me and such like it just feels depressing really.*

It is interesting that Michael identified his previous support as *‘depressing’* and that of all the young people Michael identified the least need for support as an adult. This suggests that beliefs about needing support as an adult may be dependent on how young people have previously experienced support. This statement also contrasts strongly with the views expressed by parents that, as described by Jill, *‘there's never gonna be too much support’*.

Participants' accounts about the availability of support and their experiences accessing support varied depending on what support they thought should be available. Education was identified as a key source of support now and in the future. Half of the parents had had contact with a transition social worker but described this

as being only through attendance at school meetings. Two young people had had contact with employment services. All young people expected to end their involvement with mental health services when they left CAMHS (and in one case already had) and did not describe concerns about this. In contrast, all parents either wanted or expected mental health service input to continue in some form. The majority of parents expected that a similar level of mental health service input to their experience in CAMHS would continue. In contrast, one parent (whose daughter had already left CAMHS) reported that it would only be crisis management but that more regular psychology input would be helpful. All young people reported believing they could access continued mental health service support if they needed it and that ending this support was their decision, rather than being due to service unavailability.

More generally, one young person and two parents described a belief that the support that the young person needed as an adult would be available.

*Sandra: I have been reassured all the way along at stages that have been arising with Jamie, so I don't think this'll be any different, I think by the time he's ready to leave there'll be an indication given of what's best and where next.*

However, one parent was very clear that the needed support was not available.

*Jane: You know the education system is fantastic but once they turn 18 they seem to drop off the edge of a cliff.*

Furthermore, one parent, who early in the interview expressed confidence that needed support would be available, later reported feeling that she might be being 'naïve', and another parent reported considerable uncertainty about the availability of support.

*Jill: I know it's imminent but I haven't, maybe I'm in ostrich mode at the moment, and I haven't thought of that but I really don't know what the next step is, if he will be discharged from here or if they will continue to see him.*

One area of support where all young people and parents agreed was the importance of enhanced transitions. It was described as being important that the young person was able to visit and actually see any new environment and have time, over multiple visits if possible, to adapt to changes. This had already occurred for two young people as part of their transition to college and was reported to have significantly reduced their anxiety.

*Jamie: I made use of a couple of tours ... so I have someone else take me on the tour twice of the building ... so I got to grips with the building, I learned where everything was generally, and I had an idea of what the classes were so.... judging from the time that I had at the college beforehand, also with some of the free start sessions... so by the time I went in a few weeks ago I was actually less than worried. I was actually quite confident and quite content with everything.*

This was linked both by young people and their parents to their experiences in managing previous transitions, such as the move from primary school to secondary school. Three of the parents also highlighted the need for young people to become familiar with support and how to access it before problems occur. In general the support which was, or which parents and young people wanted to be, available was characterised as background support which was not highly visible or intrusive on a day to day basis. The importance of support being provided in this way was linked to the type of support needed, which included support to avoid significant stressors, support with understanding communication and having someone to speak to or 'vent' to. However, it was also linked to what would be acceptable to the young people who, as already discussed, were reluctant to be identified as needing support and, in some cases, had had negative experiences with highly visible support such as auxiliaries. This suggests that any support provided to young people with HFASD has to be planned carefully to consider both what is needed by the young person and how it will be perceived.

#### *What it means to have ASD*

Five sub-themes were identified which were directly related to what it means to have a diagnosis of ASD: understanding/ awareness of core symptoms, multiple changes as a potential difficulty, need for people to be understanding/ aware of difficulties, normal transition compared to transition in ASD and how ASD is perceived. Young people and parents described a clear awareness of the core symptoms of ASD, including difficulties with communication, social interaction and a rigid thinking style, as well as the impact that these had on them. The majority of participants

identified multiple simultaneous changes (as happens during transition) as being potentially difficult and something that needs to be planned for.

*Mary: There's such a sort of a huge change, you know, physically in moving to another part of the world. You know, different pressures on Michael's academic focus, but equally the whole kind of way that Michael will have to function, you know, looking after himself and that sort of thing and these are quite a lot of changes that in their own right would be, you know, quite difficult for Michael to take on and they actually funnel into a very, very short space of time.*

However, it was also highlighted that the young people could adapt to change if they were supported and if change occurred gradually.

It was perceived to be important that those around the young people (both support services and more generally, for example in the work place) had an awareness of the impact of ASD, particularly difficulties with communication. The importance of this was linked to the fact that ASD is not a visible condition.

*Jane: I think sometimes that's the problem, if Fiona had a wheel chair everybody would know what to do, but because she doesn't have autism stamped on her forehead.*

There were mixed feelings, however, on the part of both parents and young people about making people aware of the diagnoses. For parents these mixed feelings were related to an awareness that their children either did not, or did not like to, identify as



being ‘disabled’. For example, Sheena described how Fiona *‘doesn’t consider herself to have a disability’* and Mary highlighted how Michael *‘doesn’t like people knowing he has autism’*. Furthermore, Jill described the importance of Mark seeing himself as *‘just an ordinary person’*. The importance of being ‘ordinary’, alongside the apparent reluctance to be identified as ‘disabled’ or ‘having autism’, suggests that ASD is perceived negatively by the participants. However, it should also be noted that all participants highlighted strengths associated with ASD. One young person described having experienced stigma around the term ‘autism’, suggesting that it may not be that the participants themselves consider having ASD to be negative but rather that they believe that ASD is perceived negatively by society.

*Michael: I suppose the ultimate sort of support would be the lack of stigma surrounding autism socially.*

A further area of debate was how many of the difficulties raised were a result of ‘normal’ transition and adolescence and how many were specific to ASD.

*Jamie: I would say half and half I have a tendency to over think things, and that could be just part of what makes me me, but it could of course be something involving the diagnosis but I’m not really sure, I would just simply say it’s 50/50.*

*Further education as a positive change*

All participants described the move to further education as either a positive change (for the two young people who had already started college) or something which they

expected to be positive. Four sub-themes were identified which related to the decision to attend further education: further education as an opportunity to socialise, further education as a practical decision, although a positive, still some concerns and uncertainty about life after college.

Further education was characterised by the majority of participants as an opportunity to socialise and develop friendships. Young people reported looking forward to meeting new people, and parents felt it provided an opportunity for young people to develop social skills and have social interactions in a structured environment.

*Fiona: Going to college would be a new experience for me to see what it's like, what they do in college ... I am liking college I've been making new friends.*

Further education was also described by young people and their mothers as a practical decision. Reasons for this included the young person not knowing what they wanted to do in terms of employment, and college providing an opportunity for the young person to try out different options through placements.

However, some concerns were still raised by parents about the impact of moving away to college or university, or by young people about the academic workload. Furthermore, three parents and two young people expressed concerns or uncertainty about life after education, in particular finding suitable employment and being without the support provided through education.

*Sheena: There is going to come a time as a young adult when suddenly she's going to have no support when she finishes at college.*

*Jane: Yeah it's going to be a huge void in her life.*

*Sheena: ... going to be like a big rug taken out from under her.*

Although not all participants described the potential impact of leaving college in such strong terms as Sheena and Jane, all participants raised the importance of structured opportunities to socialise, either through education or clubs, which will become less accessible after leaving further education. Additionally, as discussed above, all young people and parents were explicit about the difficulties with change and the need for routine experienced by young people with ASD. Therefore, it is likely that when the young people included in this study leave further education this will be a challenging time. To some extent, this suggests that any difficulties associated with the transition to adulthood may be delayed, or not fully experienced, until the end of further education (which would be between two and nine years' time for these young people). This is supported by the fact that, with the exception of Michael (who notably was planning to do a PhD and so would not experience this for at least nine years) and his mother, all participants raised some concerns about finding employment which, as described by Jill, *'will be somewhere that'll accept him as the way he is'*.

## **Discussion**

This is the first study to take a multi-perspective approach to exploring transition to adulthood for young people with HFASD, currently receiving support from CAMHS.

Using IPA to gain an understanding of how participants experienced and made sense of this transition, five main themes were identified: becoming an adult means developing independence, changing role and experience of families during transition, current and future support needs, what it means to have ASD and further education as a positive change.

Consistent with the transition experiences described by Singh et al. (2010), none of the young people in this study expected to transition from CAMHS to AMHS (and the one young person who had already been discharged from CAMHS had not been transferred to AMHS). However, in contrast to Singh et al. (2010), the majority of participants did not relate this to services not being available. Instead, it was related to the young person not needing, or wanting, ongoing mental health service input. Furthermore, the majority of participants reported a belief that, if needed, services would be available. Previous research by Singh and colleagues (2009, 2010) would suggest that this may not be realistic, and that parents may in fact be correct when they questioned if they were being 'naïve' about transition or in 'ostrich mode'. The one parent whose child had already left CAMHS raised significant concerns about future mental health input only being for crisis management. This is supported by Swift et al. (2013), who interviewed parents jointly with seven of the young people with ADHD included in their study. They reported that parents often expressed unrealistic expectations about what AMHS might provide, and highlighted the need for CAMHS clinicians to be aware of this when preparing young people for discharge.

Parents and young people described a change from previously parent led support to the young person making their own decisions about what support they

needed, although parents still had a role providing advice and facilitating access to support. This reduction in parental involvement is consistent with the experiences of the six parents (whose children had previously attended CAMHS for a range of mental health needs) interviewed by Hovish et al. (2012). However, in this case, this was not presented as a negative experience but, along with the young person making decisions about further education, an important part of the young person developing their independence. This difference may be explained by the fact that young people in this study were still receiving support from CAMHS, when parents were likely to be involved in to some degree, while those in the study by Hovish et al. (2012) had already transferred to AMHS. It may also be related to the fact that the young people included in this study were also still living at home, and in some cases expected to continue living at home for the foreseeable future. Hovish et al. (2012) reported that a significant number of the young people they included had moved out of the family home.

Some parents did raise concerns about the change to the young person taking responsibility for their own support. In particular, it was highlighted that the young person's reluctance to be identified as needing support may create a barrier to them accessing support. Only one young person directly reported being uncomfortable with being identified as needing support, seeing support as hindering him from developing independence. However, all young people reported expecting to need significantly less support as adults when compared to the support needs described by their parents. The idea that young people with HFASD are uncomfortable with being identified as needing support is supported by Humphrey and Lewis (2008), who explored the experiences of 20 young people with autism aged between 11 and 17,

using a combination of interviews and diaries. They reported that young people were often uncomfortable with highly visible support (such as auxiliaries), which increased their awareness of the differences between them and their peers.

It has been highlighted that a significant difficulty associated with transition to adulthood for young people with HFASD is the requirement to adapt to multiple changes in service provision and environments (McConachie et al. 2011; Smith et al. 2012). This study supports this theory, with participants highlighting change as an area of difficulty. Multiple changes occurring simultaneously, or changes to environments such as moving away from home or to college were key areas of anticipated difficulty. However, young people were characterised as being able to adapt to this change if supported by parents or, through enhanced transition arrangements, where they visited the new environments multiple times prior to moving.

In this study, both parents and young people reported worries about transition, including how they would manage with daily living skills if they moved away from home, the increased academic demands of further education, and employment. These worries were more prevalent in the parental accounts. It was only in the super-ordinate theme relating to the changing role and experience of families during transition that worries were a significant sub-theme in their own right. This is likely to be related to the greater perceived need for support, with parents identifying more areas in which the young person might have difficulties, which would both need support and cause them to worry. It may also reflect greater awareness on the part of the parents about the possible difficulties young people with ASD may experience as adults. This difference may impact on any services involved

in supporting young people with ASD. Support based primarily on the report or concerns of young people, as is typical within AMHS (Singh et al. 2010), may not fully address parental concerns or may underestimate the need for support. This may be detrimental to young people, as parental perception of unmet need has been found to be a significant predictor of caregiver burden, and caregiver stress is linked to an increase in ASD symptoms (Cadman et al. 2012; Smith et al. 2012).

In this study, a sub-theme concerning the impact of supporting a young person with ASD on families was identified. Parents continued to have a significant role in supporting the young person, which was greater than would be expected with a typically developing child. This supports previous research which has shown the high caregiver burden involved in supporting young people with ASD during transition (Cadman et al. 2012). A small scale study involving 11 families of children with ASD aged 15-18 has shown that support groups for parents have the potential to increase parents' perceptions of their ability to manage difficulties associated with ASD (Smith et al. 2012). However, parents in this study reported that, although they experienced difficulties and wanted support for their children, they did not want any support themselves.

Furthermore, and consistent with research conducted by Watson et al. (2013) who explored the experiences of 28 parents of young people with ASD, parents in this study were hopeful about the future. With one exception, mothers presented their worries as having decreased over the last few years as the behavioural and emotional difficulties their children experienced reduced. Additionally, all parents and young people presented the move to further education as a positive change. However, some parents and young people raised concerns about life after education, particularly

finding employment which suited the young person's strengths. These concerns may be justified, as rates of employment have been shown to be particularly low in people with ASD, with one study, which included 66 people with ASD, finding that 86% of those with comorbid psychiatric diagnoses had no day time activities (Taylor and Seltzer 2011).

### *Strengths and Limitations*

A key strength of this study is the use of dyads which allowed for an exploration of ways in which parents' and young people's perceptions of the same transition situation may differ. Furthermore, the IPA design involving in-depth interviews and analysis allowed for an understanding of the often idiosyncratic nature of transition for young people. This detailed level of analysis and comparison, both within the dyads and across participants, was facilitated by the use of a small sample size, as recommended by Smith et al. (2009). However, the small sample size limits the generalizability of these findings.

A strength of IPA is that the process through which the data is analysed can be implemented flexibly and promotes 'reflective engagement' (p80, Smith et al. 2009) with the data. Within qualitative research reflexivity is linked to the quality of research and to the credibility of findings by acknowledging the impact of the researcher on the findings (Clancy, 2013). It has been highlighted that this is particularly important when the researcher is a health care worker who might be perceived by participants as having a certain status or knowledge (Clancy, 2013). Within this study, explicit discussion with the participants about the researcher's role, supervision and reflective logs were used to promote active acknowledgement



of preconceptions. In line with the recommendations of Smith and colleagues (2009), this was done with the aim of facilitating a process of 'bracketing' this knowledge and preconceptions to promote an open minded approach to the data collection and analysis. However, as Shaw (2010) highlights, reflexivity within the context of IPA does not mean that the researcher's own experiences will not affect the results and, indeed, should not aim to achieve this. Instead, Shaw (2010) argues that a reflexive approach to the self and the relationship between the researcher and participant is part of the interpretative process from which a study's conclusions are drawn. Therefore, the results of this study should be interpreted within this context and with an awareness that the study design, data collection and interpretation will have been affected by the researcher's role and previous experience.

A potential limitation of this study is the focus on specific aspects of the transition to adulthood, which relate to the process of leaving school, the potential for moving away from home and changes to services. This is in part a reflection of the topic guide, which focused on these more concrete elements of transition in order to make the interview more accessible to young people with ASD who have social communication difficulties. To minimise the impact of this, the interview guide was used flexibly to allow more abstract areas of the transition to adulthood to be explored, such as what it means to be an adult, within the context of the concrete experiences such as leaving school or CAMHS. As discussed by Cridland and colleagues (2015), the social communication and cognitive difficulties associated with ASD can make interviewing more challenging and require questions to be broken down in a way that is not necessary for typically developing young people. At times this meant that, to facilitate understanding, the interviewer broke questions

down into closed questions which were followed with a more open question, such as 'Why is this?'. Smith et al. (2009) recommend avoiding closed questions to prevent biasing the results and, therefore, this may have impacted on the quality of the interviews.

The topic guide was developed with reference to the existing literature and, therefore, may reflect biases within this literature, such as a focus on transition within services. The development of the topic guide was discussed with researchers experienced in the use of IPA and a clinical psychologist experienced in working with young people with HFASD. However, a limitation of the study is that neither young people with ASD nor their parents were included in the development of the topic guide. Additionally, the interview guide was not piloted as the first interview was considered of sufficient quality to include in the research.

This research included only one female young person, which is consistent with the reported gender ratio of autism (Fombonne 2003). It is important to note that research has shown that there are many difficulties specifically associated with the experience of being an adolescent girl with ASD (Cridland et al. 2014). The mother of the one female participant with ASD raised these issues, but because of the requirement for themes to be present in over half the interviews this was not reflected in the final analysis. Further research is needed to build on Cridland and colleagues' (2014) analysis of the experience of girls with ASD by exploring the impact of these differences on transition. Furthermore, this study was conducted in one geographical area and with young people receiving services in one health board and council area. Previous research has shown that transition support and the availability of services varies across Scotland (Wright et al. 2015). Therefore, further research is needed to

establish whether these findings are of relevance to other service areas and what effect different service availability has on young people and their families' experiences of transition. Further research is also needed to explore whether the perceptions of young people and their parents change over the course of transition, and if the generally positive picture of services is maintained following discharge from CAMHS.

### *Conclusions*

Participants in this study describe transition to adulthood as involving the young person developing independence, with parents continuing to have a role in supporting young people to make decisions and access services. Young people and their parents perceived current and future support needs differently. Young people generally perceived less need for support, had fewer worries about the future and were reluctant to accept support. Despite this, the majority of participants felt that support from mental health services, education and employment services would be available if needed, although previous research would suggest that this position may be unrealistic, and that the expressed concerns about leaving education may be justified. Any support provided during this transition period needs to consider how this is perceived by both young people and their parents. Further research is needed to explore whether the experiences of these young people and their parents are generalizable to other young people with HFASD.

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## **Appendix 1: Relevant Autism manuscript guidelines**

### **2. Article types**

The Journal considers the following kinds of article for publication:

**1. Research Reports.** *Full papers* describing new empirical findings;

**2. Review Articles.**

*(a) general reviews that provide a synthesis of an area of autism research;*

*(b) critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.*

Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract, notes, tables, text). Editors may ask authors to make certain cuts before sending the article out for review. (Email communication confirmed that the word limit does not include references.)

### **6. Other conventions**

We would prefer to use the term ‘people with autism’ or ‘people with autism spectrum disorders or conditions’. We would also prefer the term ‘typically developing’ rather than ‘normal’.

#### **6.1 Research ethics**

All papers reporting animal and human studies must include whether written consent was obtained from the local Ethics Committee or Institutional Review Board. **Please ensure that you have provided the full name and institution of the review committee and an Ethics Committee reference number.**

We accept manuscripts that report human and/or animal studies for publication only if it is made clear that investigations were carried out to a high ethical standard. Studies in humans which might be interpreted as experimental (e.g. controlled trials) should conform to the Declaration of Helsinki and typescripts must include a statement that the research protocol was approved by the appropriate ethical committee. In line with the Declaration of Helsinki 1975, revised Hong Kong 1989, we encourage authors to register their clinical trials (at <http://clinicaltrials.gov> or other suitable databases identified by the ICMJE, [http://www.icmje.org/publishing\\_10register.html](http://www.icmje.org/publishing_10register.html)). If your trial has been registered, please state this on the Title Page. When reporting experiments on animals, indicate on the Title Page which guideline/law on the care and use of laboratory animals was followed.

#### **6.3 Statistical analyses**

Where statistical analyses have been carried out please ensure that the methodology has been accurately described. In comparative studies power calculations are usually required. In research papers requiring complex statistics the advice of an expert statistician should be sought at the design/implementation stage of the study.

## **7. Acknowledgements**

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

## **9. Manuscript style**

### **9.1 File types**

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork and supplemental files below.

### **9.2 Journal Style**

*Autism* conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

### **9.3 Reference Style**

*Autism* operates a Sage Harvard reference style. [Click here](#) to review the guidelines on SAGE Harvard to ensure your manuscript conforms to this reference style.

### **9.4. Manuscript Preparation**

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. SI units should be used throughout the text.

#### ***9.4.1 Keywords and Abstracts: Helping readers find your article online***

The title, keywords and abstract are key to ensuring that readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#).

#### ***9.4.2 Corresponding Author Contact details***

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

#### ***9.4.3 Guidelines for submitting artwork, figures and other graphics***

Artwork, figures and other graphics such as tables should be uploaded through SAGE's Online Submission System alongside the main body of the text, as a

seperate file to ensure best quality in production. For further guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

#### **9.4.4 Guidelines for submitting supplemental files**

This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

## Appendix 2: Quality criteria

<b>Methods</b>	
Sampling	<p>Well covered: Random sampling</p> <p>Adequately addressed: convenience or self-selection</p> <p>Not reported</p>
Sampling bias – general	<p>Well covered: sampling bias was assessed by the authors - differences in study population vs. target population are reported</p> <p>Adequately addressed: the authors did not assess sampling bias but justified exclusion of the subjects from the sampling or analysis</p> <p>Poorly addressed: authors make only a non-specific reference to sampling bias</p> <p>Not reported</p>
Sampling bias – gender	<p>Well covered – sample is representative of the gender ratio of the HFASD population (between 80 and 90% male)</p> <p>Adequately addressed: sample is not representative but this is justified by the study's aims or specific methodology</p> <p>Poorly addressed: sample is not representative</p> <p>Not reported</p>
Setting	<p>Well covered: describes the setting, locations, and relevant dates, including periods of recruitment</p> <p>Adequately addressed: only some of the above data reported</p> <p>Poorly addressed: sampling from multiple settings or time periods where relative contributions of different settings to the sample included are not reported</p> <p>Not addressed</p>
Participants – diagnoses of ASD	<p>Well covered: clinical interview and standardised tool (ADOS, ADI-R, DISCO etc.)</p> <p>Adequately addressed: diagnoses confirmed only by screening tool and/or clinical interview alone</p>



	<p>Poorly addressed: not confirmed by research team</p> <p>Not reported</p>
Participants – inclusion and exclusion	<p>Well covered: inclusion and exclusion criteria clearly stated and appropriate to aim</p> <p>Adequately addressed: inclusion and exclusion criteria not clearly stated</p> <p>Poorly addressed: inclusion and exclusion not appropriate to aim</p> <p>Not reported</p>
Assessment of depression	<p>Well covered: measure used has established validity and reliability within ASD population which is reported or this is established by study</p> <p>Adequately addressed: validity and reliability established within a normally developing population only</p> <p>Poorly addressed: measure is referred to as ‘commonly used’ or similar</p> <p>Not reported</p>
Decision on depression status	<p>Well covered: clear link between tools to assess depression and decision on presence of depression, details of the cut-off between depressed and not depressed, prevalence reported clearly, reported as either current or lifetime prevalence or both</p> <p>Adequately addressed: one of the above not reported</p> <p>Poorly addressed: two of the above not reported</p> <p>Not reported</p>
<b>Results</b>	
Participants	<p>Well covered: reports numbers of individuals at each stage of study — e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study and analysed including response rates</p> <p>Adequately addressed: some of the above not addressed</p> <p>Poorly addressed: majority of the above not reported</p> <p>Not reported</p>

Descriptive data – general	<p>Well covered – give characteristics of study participants (e.g. demographic, clinical, social)</p> <p>Adequately addressed – only some characteristics reported</p> <p>Poorly addressed – not reported in appropriate detail</p> <p>Not reported</p>
Descriptive data – medication use	<p>Well covered: use of anti-depressants and other medication reported separately and the effect on the results considered</p> <p>Adequately addressed: use of anti-depressant medication reported but effect on results not considered</p> <p>Poorly addressed: medication only reported in general terms (i.e. psychoactive medication)</p> <p>Not reported</p>
Descriptive data – comorbidities	<p>Well covered: comorbidities in the sample (including ADHD and anxiety) reported separately and the effect on the results considered</p> <p>Adequately addressed: comorbidities reported but effect on results not considered or only effect of one comorbidity considered</p> <p>Poorly addressed: only some comorbidities reported (i.e. only ADHD)</p> <p>Not reported</p>

### Appendix 3: Coding of quality according to criteria detailed in Appendix 2

Referen ce	Methods								Results				
	Sam pling	Samp ling bias – gener al	Samp ling bias – gende r	Setti ng	Partici pants – diagnos es of ASD	Partici pants – inclusio n and exclusi on	Assess ment of depress ion	Decisio n on depres sion status	Partici pants	Descri ptive data - genera l	Descri ptive data – medica tion use	Descript ive data – comorbi dities	score (total possible - 24)
Giovina zzo et al. (2013)	AA	NR	WC	WC	WC	NR	AA	NR	NR	AA	AA	AA	11
Green et al. (2000)	AA	WC	AA	AA	WC	WC	PA	WC	NR	WC	AA	AA	15

Gurkan et al. (2008)													
	AA	WC	WC	AA	AA	WC	AA	WC	NR	AA	AA	AA	15
Hebron and Humphrey (2014)													
	WC	NR	WC	AA	PA	WC	AA	AA	AA	AA	NR	WC	13
Joshi et al. (2014); Joshi et al. (2010)													
	AA	WC	WC	WC	AA	AA	AA	WC	WC	WC	PA	AA	17
Kim et al. (2000)													
	AA	AA	WC	AA	WC	WC	AA	WC	WC	AA	NR	AA	16
Lopata et al. (2010)													
	AA	WC	WC	PA	WC	WC	AA	WC	NR	WC	NR	PA	14

Mattila et al. (2010)	WC	AA	WC	WC	WC	WC	AA	WC	WC	AA	NR	WC	19
Mazefsk y et al. (2011b) <sup>b</sup>	AA	AA	WC	AA	WC	WC	WC	WC	NR	AA	WC	AA	17
Mazzon e et al. (2013)	AA	AA	PA	AA	WC	AA	AA	WC	NR	AA	NR	PA	10
Mukadd es and Fateh (2010)	AA	PA	PA	WC	AA	WC	AA	WC	WC	AA	NR	AA	13
Mukadd es et al. (2010)	AA	AA	WC	WC	AA	WC	PA	WC	NR	AA	NR	WC	14
Strang et al. (2012)	AA	NR	WC	AA	WC	WC	AA	WC	NR	AA	WC	AA	15

Vickerst aff et al. (2007)	AA	WC	WC	AA	WC	WC	AA	WC	AA	WC	NR	NR	16
Whiteho use et al. (2009)	NR	NR	WC	AA	AA	AA	AA	WC	NR	AA	NR	NR	9
Wilson et al. (2014)	AA	AA	WC	PA	AA	WC	AA	WC	NR	AA	NR	WC	13
Witwer and Lecavali er (2010)	AA	AA	WC	PA	WC	WC	AA	WC	NR	WC	AA	AA	15

WC: well covered (2 points)

AA: adequately addressed (1 point)

PA: poorly addressed (0 points)

NR: not reported (0 points)

## **Appendix 4: Relevant instructions for authors for the Journal of Autism and Developmental Disorders**

### **MANUSCRIPT FORMAT**

All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins.

#### **APA Style**

Text must be double-spaced; APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, **DO NOT** include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.

The blinded manuscript containing no author information (no name, no affiliation, and so forth).

#### **The Author Note**

#### **Types of papers**

Articles, Brief Reports, Letters to the Editor, Commentaries

The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.

#### **Abstract**

Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

#### **Keywords**

Please provide 4 to 6 keywords which can be used for indexing purposes.

#### **Text Formatting**

Manuscripts should be submitted in Word.

Use a normal, plain font (e.g., 10-point Times Roman) for text.

Use italics for emphasis.

Use the automatic page numbering function to number the pages.

Do not use field functions.

Use tab stops or other commands for indents, not the space bar.

Use the table function, not spreadsheets, to make tables.

Use the equation editor or MathType for equations.

Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

## Body

The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:

Introduction (The introduction has no label.)

Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)

Results (Center the heading.)

Discussion (Center the heading.)

## Headings

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

## Footnotes

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.



Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

#### Citation

Cite references in the text by name and year in parentheses. Some examples:

Negotiation research spans many disciplines (Thompson 1990).

This result was later contradicted by Becker and Seligman (1996).

This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).

#### Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

Reference list entries should be alphabetized by the last names of the first author of each work.

#### Journal article

Harris, M., Karper, E., Stacks, G., Hoffman, D., DeNiro, R., Cruz, P., et al. (2001). Writing labs and the Hollywood connection. *Journal of Film Writing*, 44(3), 213–245.

#### Article by DOI

Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. *Journal of Molecular Medicine*, doi:10.1007/s001090000086

#### Book

Calfee, R. C., & Valencia, R. R. (1991). *APA guide to preparing manuscripts for journal publication*. Washington, DC: American Psychological Association.

#### Book chapter

O'Neil, J. M., & Egan, J. (1992). Men's and women's gender role journeys: Metaphor for healing, transition, and transformation. In B. R. Wainrib (Ed.), *Gender issues across the life cycle* (pp. 107–123). New York: Springer.

#### Online document

Abou-Allaban, Y., Dell, M. L., Greenberg, W., Lomax, J., Peteet, J., Torres, M., & Cowell, V. (2006). Religious/spiritual commitments and psychiatric practice.

Resource document. American Psychiatric Association.  
[http://www.psych.org/edu/other\\_res/lib\\_archives/archives/200604.pdf](http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf). Accessed 25 June 2007.

Journal names and book titles should be italicized.

For authors using EndNote, Springer provides an output style that supports the formatting of in-text citations and reference list.

#### Tables

All tables are to be numbered using Arabic numerals.

Tables should always be cited in text in consecutive numerical order.

For each table, please supply a table caption (title) explaining the components of the table.

Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.

Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

## Appendix 5: Ethics approval from the NHS National Research Ethics Committee, North of Scotland

**NRES Committees - North of Scotland**  
Summerfield House  
2 Eddy Road  
Aberdeen  
AB15 6RE

Telephone: 01224 558458  
Facsimile: 01224 558609  
Email: [nres@nhs.net](mailto:nres@nhs.net)



10 March 2014

Miss Alice Wright  
The Rowan Centre  
The Glassgreen Centre  
2 Thornhill Drive  
ELGIN  
Moray  
IV30 6GQ

Dear Miss Wright

**Study title:** Exploring transition to adulthood from the perspective of young people with high functioning autism spectrum disorders and their families  
**REC reference:** 14/NS/0032  
**IRAS project ID:** 137826

Thank you for your letter which we received on 10 March 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 4 March 2014.

### Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		10 March 2014*
Participant Information Sheet: Young People	3	6 March 2014
Participant Information Sheet: Parents	3	6 March 2014

\* date received

### Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Covering Letter		10 March 2014*
Interview Schedules/Topic Guides	1	2 December 2013

\* date received

Document	Version	Date
Investigator CV		13 February 2014
Unfavourable Opinion Letter		3 February 2014
Covering Letter		13 February 2014
Emily Frances Newman - CV		2 December 2013
Ethel Quayle - CV		2 December 2013
Dr Chris Wille - CV		17 February 2014*
Participant Consent Form: Family Member	2	5 February 2014
Participant Consent Form: Young People	2	5 February 2014
Participant Information Sheet: Young People	3	6 March 2014
Participant Information Sheet: Parents	3	6 March 2014
Protocol	2	3 February 2014
REC application	137826/566 159/1/424	17 February 2014
Referees or other scientific critique report		7 August 2013

\* date received

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/NS/0032

Please quote this number on all correspondence

Yours sincerely



**Mrs Carol Irvine**  
Ethics Co-ordinator

Copy to: Professor Charlotte Clarke  
NHSG R&D Department

## **Appendix 6: Participant information sheet for young people.**

### **Exploring transition to adulthood from the perspective of young people with high functioning autism spectrum disorders and their families**

**You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. You can take as long as you want to decide and you can talk to somebody else about it if you wish. If you have any questions let us know.**

#### **What is the study about?**

This study is trying to find out what young people with high functioning Autism Spectrum Disorders (including Asperger Syndrome) who attend Child and Adolescent Mental Health Services (CAMHS) think about the changes that will happen when they leave school and children's services. We want to find out if you and your family have any worries about this and whether you might need any extra support.

#### **Why have I been asked to take part?**

You have previously been diagnosed with a high functioning Autism Spectrum Disorder (Autism without a Learning Disability), such as Asperger Syndrome or High Functioning Autism, and you have been going to CAMHS clinics.

#### **Do I have to take part?**

No, you don't have to take part. If you do want to take part you will be given this information sheet to keep and we will ask you to sign to say you want to take part. If you do decide to take part, you can stop taking part at any time and you don't have to tell us why. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive. It is up to you.

#### **What will happen if I take part?**

If you do want to take part we will ask you to have a chat with a researcher during which you will be asked some questions and you will have the opportunity to give your opinions. This can be either at your own house or in a health centre or hospital. This will take about 30-60 minutes. What you say will be recorded if that is OK. You only have to answer the questions you want to.

This study is also trying to find out what your parents, or someone else who looks after you, thinks. To allow us to do this we would like you to say which person you want us to talk to. They will be asked the same questions as you and both you and a parent need to take part.

**Will it help me if I take part?**

We don't think taking part will help you directly but finding out what young people and their families think will help to improve things for other young people who are in the same situation as you.

**Are there any risks of taking part?**

We do not think there are any risks to you if you take part.

**What if there is a problem?**

If you are worried about any part of the study you can contact Alice Wright, who is the researcher conducting this study. Her email address is: s1269818@sms.ed.ac.uk and her phone number is 01343 553111. Or you can contact Emily Newman who is in charge of the study, her email address is: emily.newman@ed.ac.uk.

**What happens when the study is finished?**

Everything the young people and their parents say will be written down using the audio recordings. This will allow us to see what things are causing most concern to most people. This will help show what support most young people and their families might need in the future. The study will be also written into a report for a Doctoral degree for the researcher and will be sent to a journal for publishing. If you want to know what we find we can send you a short version of the results when the study is finished.

**Will other people know what I have said?**

All your information and everything you say will be kept completely confidential. Nobody will know your name or what you have said. Your name won't be in any reports. The only time we would have to tell anyone else is if we thought you, or someone else, was in danger.

**Who is organising the research?**

This study is organised by NHS Grampian and the University of Edinburgh.

**Who has reviewed the study?**

The research has been checked by a group of people, called a Research Ethics Committee who make sure the study is OK. This study was approved by NRES Committees - North of Scotland (1).

**How do I take part?**

If you want to take part in this study please fill in your name and address on the form and we will get in touch with you.

Thank you for taking the time to read this.

## **Appendix 7: Participant information sheet for parents**

### **Exploring transition to adulthood from the perspective of young people with high functioning autism spectrum disorders and their families**

**You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. You can take as long as you want to decide and you can talk to somebody else about it if you wish. If you have any questions let us know.**

#### **What is the study about?**

This study is trying to find out what young people with high functioning Autism Spectrum Disorders (including Asperger Syndrome) who attend Child and Adolescent Mental Health Services (CAMHS) think about the changes that will happen when they leave school and children's services. We want to find out if you and your child have any worries about this and whether you or your child might need any extra support.

#### **Why have I been asked to take part?**

You have been asked to take part as your child has been previously diagnosed with a high functioning Autism Spectrum Disorder (Autism without a Learning Disability), this could be Asperger Syndrome or High Functioning Autism, and he/she is currently attending Child and Adolescent Mental Health Services.

#### **Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you do decide to take part, you can stop taking part at any time and you don't have to tell us why. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive. It is up to you.

#### **What will happen if I take part?**

If you want to take part you will be asked to attend an interview with the researcher at a time that suits you. This can be either in your home or at a local NHS building. The interview with the researcher will take about 30-60 minutes. What you say will be recorded if that is OK. You only have to answer the questions you want to.

#### **Will it help me if I take part?**

We don't think taking part will help you but if we can find out what young people and their families think it will help improve things for other families who are in the same situation as you.

#### **Are there any risks of taking part?**

We do not think there are any risks to you if you take part.

**What if there is a problem?**

If you are worried about any part of the study you can contact Alice Wright, who is the researcher conducting this study. Her email address is: [s1269818@sms.ed.ac.uk](mailto:s1269818@sms.ed.ac.uk) and her phone number is 01343 553111. Or you can contact Emily Newman who is in charge of the study, her email address is: [emily.newman@ed.ac.uk](mailto:emily.newman@ed.ac.uk).

**What happens when the study is finished?**

Everything the young people and their parents say will be written down using the audio recordings. This will allow us to see what things are causing most concern to most people. This will help show what support most young people and their families might need in the future. The study will be also written into a report for a Doctoral degree for the researcher and will be sent to a journal for publishing. If you want to know what we find we can send you a short version of the results when the study is finished.

**Will my taking part in the study be kept confidential?**

We will keep all your information and everything you say completely confidential. Nobody will know your name or what you have said. Your name won't be in any reports. The only time we would have to tell anyone else is if anything you or your child raises indicates they or someone else is at risk. If this is the case any concerns will initially be discussed with a clinician within the research team, Chris Wiles (Consultant Clinical Psychologist, Rowan Centre, Elgin). If following this further action is needed, relevant professionals will be contacted.

**Who is organising the research?**

This study is organised by NHS Grampian and the University of Edinburgh.

**Who has reviewed the study?**

The research has been checked by a group of people, called a Research Ethics Committee, who make sure the study is OK. This study was approved by NRES Committees - North of Scotland (1).

Thank you for taking the time to read this.



## Appendix 8: Consent form for young people

### CONSENT FORM

#### Exploring transition to adulthood from the perspective of young people with high functioning autism spectrum disorders and their families

**Researcher: Alice Wright**

email: s1269818@sms.ed.ac.uk

Address: The Rowan Centre, The Glassgreen Centre, 2 Thornhill Drive, Elgin, IV30 6GQ

**Please initial box**

1. I confirm that I have read and understand the information sheet (version 2) for the above study and have had the opportunity to consider the information and ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

3. I understand that data collected during the study may be looked at by individuals from the Sponsor, from the NHS organisation or other authorities, where it is relevant to my taking part in this research.

☐

4. I understand that my participation will be audio recorded.

☐

5. I agree to the use of anonymised quotes for publication and other scholarly uses.

☐

6. I agree to a parent (or person with parental responsibility) of my choice being interviewed about my transition to adulthood.

☐

7. I agree to take part in the above study

☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent	Date	Signature

If you would like a general summary of the results following the completion of this study please indicate bellow and provide a postal address:

Yes I would like a copy of the result ☐

Postal address :

_____
_____
_____
_____

## Appendix 9: Consent form for parents

### CONSENT FORM

#### Exploring transition to adulthood from the perspective of young people with high functioning autism spectrum disorders and their families

**Researcher: Alice Wright**

email: s1269818@sms.ed.ac.uk

Address: The Rowan Centre, The Glassgreen Centre, 2 Thornhill Drive, Elgin, IV30 6GQ

**Please initial box**

1. I confirm that I have read and understand the information sheet (version 2) for the above study and have had the opportunity to consider the information and ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

3. I understand that data collected during the study may be looked at by individuals from the Sponsor, from the NHS organisation or other authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

☐

4. I understand that my participation will be audio recorded.

☐

5. I agree to the use of anonymised quotes for publication and other scholarly uses.

☐

6. I agree to take part in the above study

☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent	Date	Signature

If you would like a general summary of the results following the completion of this study please indicate bellow and provide a postal address:

Yes I would like a copy of the result ☐

Postal address:

_____
_____
_____
_____

## Appendix 10: Interview topic guide

### Interview Topic Guide

1. Can you tell me a bit about your life just now?  
*Possible prompts:* Are you at school? Who do you live with? What do you enjoy doing outside of school?
2. Can you tell me about support you/your child receive(s) at the moment?  
*Possible prompts:* Are you supported by mental health services?  
In school? By social services?
3. What do you expect to happen when you/ your child leave school?
4. What do you expect to happen when you/ your child leaves children's services/ CAMHS?
5. Can you describe what you expect to happen when you/ your child transitions out of children's services?  
*Possible prompts:* What do you expect to happen when you leave school?
6. What support do you think you will need during this transition?  
*Possible prompts:* has anyone ever discussed transition with you before?  
What support do you think you need from mental health services?  
What support do you need from school? Anyone else?  
When should support start/ at what age?
7. Are there any aspects of this transition you are worried about?
8. Young person - What are your plans for your life after school?  
Family – What do you expect to happen when your child leaves school?  
*Possible prompts:* do you plan to continue with education/ start work?  
Where do you plan on living? What other things will be important to use as an adult? Friendships?
9. What support (if any) do you think you will need as an adult?

## **Appendix 11: Extracts from reflective log**

### **Sample of reflections while coding transcripts**

#### **YP03**

Straight away aware of how articulate and high functioning this young person is – in some ways a lot more able than the other participants but still shows a very ‘autistic’ style of speaking. Also very reflective, and has great insight into the situation. In some ways this feels quite contradictory to how autism is often presented in the literature. Really interesting interview.

- Very clear that would not want support as an adult – idea that support can in some ways be hindering – how does this fit with underlying assumption in the literature/ services (and sometimes by me) that lack of support is a bad thing? Have to actively try and ‘bracket’ my preconceptions about support and my knowledge of the literature around transition.
- Very aware of label and what it might mean and how it might impact on him and people perceptions of him. ?how much of this is relevant to the research question? How to present this? What does this mean about the interview? How did he feel about being interviewed for research on ASD which he was asked to take part in purely because of his ‘label’?
- Can’t escape the feeling that this YP could do very well at university and the perception that for him transition is a positive thing that will bring a lot of opportunities – thinking about how well he would have fit in at university - ?reflection of my own personal experiences of seeing friends with ASD do well at university or the optimism he feels? Again importance of being aware of my own preconceptions and experiences, both clinical and personal with people with

ASD and trying to bracket these and move to making sense of this young person's experience.

### **PT03**

Quite a different account to YP but aware of difference. This dyad are the only one's explicitly acknowledge their different opinions, Mum refers to the balance between her agenda and his.

- Have to be aware of my temptation to 'side' with the YP – influenced by my personally beliefs about importance of developing independence and my clinical work. Hard to separate how I would view this as a clinician (knowledge about importance of developing independence, encouraging young person to take more responsibility for managing support) and interpreting this as a researcher where my focus is on 'making sense of' her experiences.
- Mum clearly quite conflicted over her role – wants to make sure support is there but also wants him to develop independence – difficult position to be in. Quite aware of my own feelings and awareness (from literature and personal experience) of how justified some of her concerns are.
- Quite ironic 'I don't imagine there's a gap' – when so many articles about transition are titled things like 'mind the gap' and talking about falling off a cliff. Again have to be aware of my knowledge of the literature and the impact this might have on my interpretations.

### **PT03 compared to YP03**

Only dyad to be very explicit and aware of the differences in their opinions and perceptions

- Clearest area of disagreement is around support.
- Although overall themes very similar detail is different, YP expecting to need significantly less support and to be significantly more independent.
- Clear differences in how they view issues – YP stating that these are more just about transition while parent clear that transition is different for people with ASD.
- Mum viewing change and the unknown as a potential problem – YP viewing it as something to look forward to.

### **Sample reflections on overall thematic structure**

Overarching theme of the change from parent-led processes to young-adult-led or ‘gaining independence and taking decisions’ or ‘young person developing self-reliance’ (in the words of YP02). The transition is very much characterised this way rather than as one from childhood to adulthood or from one service to another, with the different YP at various stages of this depending on age and ability level.

Support – what is needed is much more about people being understanding and not having stigma towards autism rather than anything actually happening. Parents seem to see future support provided by services (mainly employment support, education and psychology) as important to adults with autism but YP much less certain. Is this normal parents being more worried than children?



Overall all have a belief that if support is needed it will be there – naïve or a reflection that services are changing, services for adults with ASD are developing? Have to be aware of my own preconceptions, particularly my experience of working on adult mental health services in this area and my own knowledge that support for adults with ASD is often not available.

Difficulty of balancing individual stories and concerns – which are a large extent representative by the YP's circumstance – if they are moving away from home, what their current support is etc and creating overall themes and structure which reflects their common concerns. IPA focus on both similarities and difference but how to capture this?